ADHERENCE TO TREATMENT AMONG ADOLESCENTS WITH CHRONIC ILLNESS

A PROSPECTIVE STUDY

A dissertation submitted to the Tamil Nadu Dr. M. G. R. Medical University in partial fulfilment of the requirement for the award of M.D. (Paediatrics) degree

April 2015 – 2017.

CERTIFICATE

This is to certify that this dissertation titled "**ADHERENCE TO TREATMENT AMONG ADOLESCENTS WITH CHRONIC ILLNESS"** is a bonafide work done by **Dr. A. BETSY SHERBA** in Christian Medical College, Vellore in partial fulfilment of the rules and regulations of the Tamil Nadu Dr. M. G. R. Medical University for the award of M.D. Degree in Paediatrics under my supervision and guidance during the period of her post graduate study from April 2015 to March 2017.

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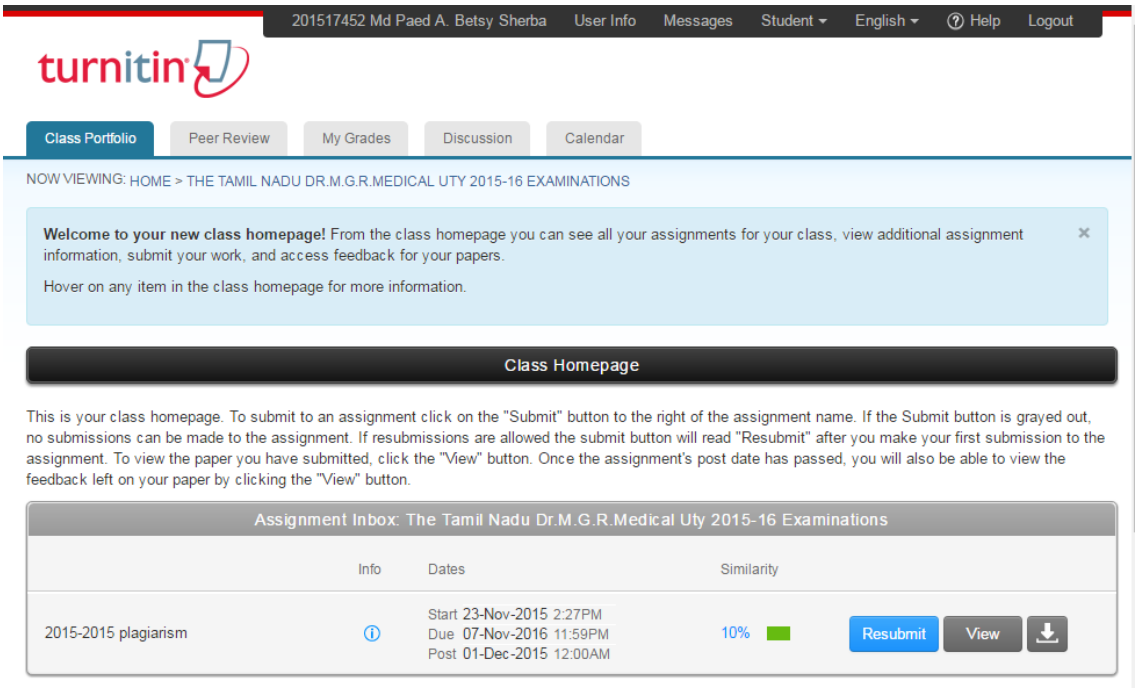


CONTENTS

INTRODUCTION

1. INTRODUCTION

Adolescence is a transitional phase between a dependent childhood and an independent adulthood, during which time numerous changes occur in the physical, psychological, emotional and cognitive domains. It is a phase when there is a move towards developing individual identity. In a small proportion of the adolescents this is also a period of turbulence, discoveries, independent decision-making and internal conflicts. In the presence of a chronic illness, these normal chaotic changes have a much bigger effect on the mind and body of the young person. Understandably it is difficult for the adolescent to accept the illness, because of the chronicity and the treatment regimen. The normal changes and conflicts that is typical of this transition period intensifies turmoil. This inner turmoil is reflected on social interactions, daily activities, sexuality and interpersonal relationships, creating physical and psychological limitations (1).

Poor compliance can result in significant morbidity and mortality among adolescents with chronic illness. Protective factors for good compliance include family and friends support, emotional stability, support from school and support in the health care setting. In order to promote good adherence, it is essential for the treating team to understand the dynamics between an adolescent patient, family, peers, school, psychosocial developmental stage the adolescent is in and awareness regarding their own illness.

Literature in Adolescent medicine and chronic illness in adolescents in India is sparse. Studies in this area is important, more so in the Indian context. Research is

needed to understand timing, when, how and how soon a young person can assume primary responsibilities for their own care (2).

Since research in our country is non-existent in adolescents with chronic illness among our adolescent patients, this study was designed to evaluate adherence rates among adolescents who presented to the various paediatric subspecialty outpatient clinics in the Paediatric Department, in Christian Medical College, Vellore. It was conducted to understand the various factors that influence adherence and to understand perceptions of adolescents with chronic illness about disease and their experience while living with the illness. Studies have demonstrated that many similarities occur in the lived experiences of adolescents with different types of chronic illness. Most of the consequences of a chronic illness are independent of the specific illness the young person suffers from (3). Hence without specifying disease, using a quantitative research method, adherence to treatment in adolescents with different types of chronic illness was studies**.** Quantitative study was conducted using the validated 8 score Modified Morisky Medication Adherence Scale (MMAS) and a qualitative research was done using focus group discussions.

AIMS

2. AIMS

1. To assess adherence rate to treatment among adolescents with chronic illness, using MMAS questionnaire.

2. To assess factors contributing to non-adherence among the same group of adolescents using another questionnaire developed by the researchers.

3. To evaluate non-adherence and perceptions about the disease using qualitative research methodology.

OBJECTIVES

3. OBJECTIVES

To assess the rates of adherence to treatment in adolescents with chronic illness attending the various sub specialty outpatient clinics of the Paediatric Department at Christian Medical College, Vellore, from November 2015 – June 2016 by quantitative and qualitative methods.

LITERATURE REVIEW

4. LITERATURE REVIEW

Adolescence

World Health Organization (WHO) defines adolescence arbitrarily as the period between 10 and 19 years of ages (4). It spans beyond 19 years and up to the mid-twenties, by which time research indicates that the adolescent brain has reached a good level of maturity. A person is considered a young adult till 30 years.

Adolescence can be divided into 3 phases based on psychosocial developmental features: early, middle and late adolescence. Each of the adolescent stages is characterised by unique biological, psychological and social behaviours (5).

Adolescence is a time of rapid physical, cognitive, emotional and social development (6). The physical component of maturation is striking and well characterized because of the pubertal changes in the body. However, it is not always appreciated that equally important changes are occurring in the cognitive, emotional and social domains. These changes occuring throughout the adolescent and young adult years has a significant effect on the delivery of health care to patients in this age group (6). The extent to which a young person has developed abstract thinking and an identity separate from their family determines their capacity to engage with an adult health-care system. This typically refers to the health care system in the west. In India, family involvement continues to a large extent in the health care of a person whatever the age be.

The adolescent brain

Research using MRI studies and animal models in the last 3 decades have revolutionized the field of adolescent neurobiology. These studies show that myelinogenesis, an essential feature for proper insulation and efficient neurocybernetics, continues from childhood. This brain maturation is at its peak in adolescence and young adulthood. Studies have revealed that the brain's region-specific neurocircuitry connections are structurally and functionally vulnerable to impulsive behaviour. This maturation of the adolescent brain is also influenced by genetic, environment, and hormonal (estrogen, progesterone, and testosterone) factors. Glutamatergic neurotransmission is shown to predominate in the adolescent brain whereas the GABA neurotransmission remains under construction. This might explain the immature and impulsive behaviour and neurobehavioral excitement during adolescent life (7).

'Pruning' is another important aspect needed for brain maturation. Longitudinal MRI studies have established a second surge of neuronal growth by grey matter thickening, that occurs just before puberty (8). This surge is similar to what happens during infancy and consists mainly of thickening of grey matter. Following proliferation, the brain rewires itself from onset of puberty up until 24 years old, especially in the prefrontal cortex. This is accomplished by dendritic pruning and myelination. Dendritic pruning essentially is a beneficial process which removes unused synapses.

Although genes play a role in the decline in synapses, animal research has shown that experience also shapes the decline. Synapses "exercised" by experience survive and are strengthened, while others are “pruned” away (9). Pruning may reveal genetically or experientially vulnerable circuits. The process of pruning may explain the finding that most major psychiatric disorders of thought, mood, and anxiety have their onset during adolescence.

Studies have demonstrated a differential growth rate between different areas in the brain. Temporal lobe matures much ahead of the prefrontal cortex (PFC). Areas involved in more basic functions mature first and parts of brain responsible for more "top-down" control, controlling impulses and planning ahead (the hallmarks of adult behaviour) are among the last to mature (9). The PFC of adolescent brain, the seat of mature executive functioning, develops only in the early to mid-twenties. Amygdala which drives impulsive behaviour and emotional reactions matures much earlier. This is the reason behind the apparent high risk behaviour, typical of adolescence (10).

Adolescent perceptions of people around them and their resultant experiences seem particularly different from adult perceptions. In a study conducted at McLean Hospital, Boston, psychologist Deborah Yurgelun-Todd and team showed pictures of people having fearful expressions to adolescents between 11 and 17 years of age while their brains were scanned using fMRI (11). They noted that compared to adults their frontal lobe was less active and amygdala (structure in the temporal lobe that enables in discriminating fear and other type of emotions) was more active. 74% of the adolescents correctly identified the type of affect that was presented. The remaining had categorized the affect with various other types of expression. It was observed in

this study that adolescent subjects had difficulty in consistently identifying correct facial expression in spite of having significant activation. LeDoux (1991, 1994) had suggested that the amygdala is one of the structures that is needed for attaching emotional significance to a stimulus, a process which is essential for successful development (11). Studies done later have also revealed that adolescents in their early and middles adolescent years, misinterpret even day to day emotional reactions of adults such as sadness and anger.

The significance of the transition to adult health care setting

Transition to adult health care basically implies helping adolescents to realise their emerging capacity for self-management. The ability to self-manage, among adolescents with chronic conditions, is correlated well with self efficacy (12). Transition from parent being the primary care giver with all the responsibility to the adolescent assuming that responsibility, requires modification in the approach of the health care team to maximise results. It is essential for us as health care professionals to understand the capacities that an adolescent has been endowed with and facilitate a smooth transition from a parent oriented care to self-care during adolescence. This is particularly important in the west; not typically so in India.

Different countries have different policies regarding the age at which they accomplish a transition into adult health care system. More studies are needed to understand the relevance of such a timing, the nature of the transition and the speed with which the transition should occur in our country. Transition to adult care setting may evolve as an important issue over time, with a shift in cultural paradigm.

Definition of Chronic illness in an adolescent

The American Academy of Paediatrics defines chronic illness in childhood and adolescence as "diseases that affect a person for an extended period of time, often for life, and that require medical care and attention above and beyond the normal" (13). Stein and colleagues proposed a framework based on three definitional concepts that must coexist for an adolescent to be classified as having a chronic condition (14). Chronic illnesses are defined as disorders that:

1. Have a biological, psychological, or cognitive basis,
2. Have lasted or are expected to last for at least 1 year,
3. Produce one or more of the following sequelae:
    a) Limitation of the routine function, activities, or social role when compared to the healthy individuals in areas of physical, cognitive, emotional and social growth and development.
    b) Presence of dependency on one of the following to minimise the limitation of function, activities, or social role: (i) Medications (ii) Special diet (iii) Usage of Medical technology (iv) Assistive device (v) Personal assistance.
    c) Need for medical care or related services, psychological services, or educational services over and above the usual for the adolescent's age, or for special ongoing treatment, interventions, or accommodations at home or in school.

The magnitude of problem of 'adolescents with chronic illness

Chronic illness affects 10–20% of patients during their childhood and adolescence (15). Incidence and prevalence of chronic illnesses is on the rise in most countries and is estimated to become a major cause of mortality by 2020 (16). The WHO manual, 2007 on adolescents with chronic illness, based on self-reported questionnaire study done among school going adolescents in several countries reports that chronic illness is more prevalent among males, rural areas, socioeconomically marginalised groups, adolescents from impoverished areas and from less educated families. This finding is of limited value, since the survey did not include adolescents who were severely ill and unable to attend school (5).

Life expectancy of children and adolescents has increased due to significant improvement in nutrition, environmental hygiene and good control of infectious diseases. There is a resultant simultaneous epidemiological transition, with non-communicable diseases emerging as a more important public health problem in many countries. Hence incidence of all the chronic illness among adolescents is on the rise since the latter half of 20^{th} century. And there is also an increase in the number of adolescents with chronic illness due to the effect of the advances made in therapeutics, as more children with chronic illness survive into adolescence.

Management of an adolescent living with a chronic illness is a challenge for the adolescent, their family and health care team. The reason for this difficulty is the inherent but normal changes in the various domains during adolescence, which includes the need for an adolescent to establish an autonomy and an identity separate from the family (5).

Unlike chronic illness among adults, many of the chronic illnesses in adolescents are not preventable by life style changes. Diabetes mellitus, HIV, psychiatric illnesses, malignancies are increasing in incidence in adolescence (2). Many conditions which were considered fatal earlier, for e.g. congenital heart disease, cystic fibrosis has better survival rates beyond childhood.

Challenges for an adolescent living with a chronic illness

Health related issues in adolescents with chronic illnesses is complex. The reason for such complexity involves the illness per se, psychosocial developmental intricacies of the phase of adolescence and the problems generated by an inevitable interaction between illness, adolescent and the milieu they live in (2). The usual demands during the adolescent age include adjustment to physical changes, sexual awakening, establishing identity, identification with a peer group, development of self-dependence, gradual separation from family in various responsibilities, development of abstract reasoning skills, formal operational thought and focussed planning for the future (17). For an adolescent with chronic illness, managing their disease becomes a huge added demand. Chronic illness in an adolescent also prevents a smooth transition through the 3 stages of the adolescence (5). The normal physiological and psychosocial changes themselves can have an impact on disease process. It thus becomes essential for the treating team to understand this complexity. If the adolescent medical team is aware of the problems and the complex interaction between the physical illness and the psychosocial factors, then they will efficiently address each need, thereby effectively manage an adolescent with chronic illness.

Little is known about how best these can be supported in a health care setting (2). This field warrants wider research and awareness among health care professionals.

Effects of chronic illness on adolescence

A. Biological development

1. Chronic illness can cause a decrease in growth velocity which either transient or permanent stunting. The factors attributed to these effects are nutritional deprivation, accumulation of toxins (high blood sugar levels in Type 1 Diabetes Mellitus; interference with IGF-1 production), down-regulation of pituitary hypothalamic hormones (gonadotrophins, growth hormone) due to chronic inflammation, stress (reduces GH production) and cytokine production (e.g. in JRA).

2. Delay in pubertal growth

3. Decrease in bone mass accretion

B. Psychological development

Severity of illness and intensity of treatment protocols influence the overall wellbeing of an adolescent with a chronic illness. Several studies have analysed the various psychological and psychosocial effects resulting from a chronic illness. Adolescents living with chronic illness have a higher risk for mental health and adjustment issues.

A meta-analysis conducted by Lavigne and Gaier Routman reported a higher prevalence of psychological adjustments and internalizing symptoms in adolescents

with chronic illness when compared with healthy controls (18). Major psychiatric disorders are also more common among adolescents with chronic illness. At a less severe level, these adolescents also tend to adopt a sick role as a personal identity. (19).

C. Cognition

Identity of self, self-image and ego development are all affected by chronic illnesses in a generic fashion. Body image and sexual development are also similarly affected (20). Some studies report a higher incidence of body dissatisfaction among adolescents with chronic illness. They tend to adopt unhealthy weight losing measures (21).

D. Scholastic performance

Chronic illness greatly affects the school attendance and the scholastic achievement. This on a long term can lead to vocational impairments and the inability to financial self-sustainment in later adulthood. Surprisingly often, adolescents and their families prioritize education over medical treatment. This could lead to missing OPD appointments, discontinuing medications, refusal to take medication in school premises, being late for follow up laboratory tests. All these in turn result in poor compliance (22). School absenteeism because of a chronic illness varies from 13% for patients with orthopaedic problems to 35% for those adolescents living with cancer (23) Adolescents with asthma seem to have a lower than average academic performance compared to peers (24).

E. Family and peer relationship

Adolescents with a chronic illness understandably cause an increase in parental stress (254).Their dependency on other family members because of the illness increase during a phase in life when they are supposed to become more independent. Peer group support is essential during this period of intense socialization (26). Adolescents who do not experience a good peer relationship during this phase will develop social isolation, which can lead to a vicious cycle of mood disturbances in turn leading to poor compliance.

Effect of adolescent specific developmental changes on course of chronic illness

Normal developmental changes during adolescence can affect both management and course of chronic illness and hence the final outcome.

A. Impact of pubertal growth

Puberty and the growth spurt impose a considerable calorific and metabolic burden upon a healthy adolescent body. Studies done in adolescence with diabetes mellitus have shown that adolescence is a crucial period when glycaemic control deteriorates and maintaining euglycaemia in this age group is extremely difficult. Risk of developing diabetes related complications tend to increase during this period (27). Several studies have demonstrated that poor control of blood sugars is related to physiological changes that occurs during this period of growth acceleration (*28).* The tremendous physical growth that occurs can be an added burden on an ill adolescent, and can destabilize the chronic disease. Also the pharmacodynamics of medications

can alter due to the rapid pubert.al growth rate and changes in hepatic and renal metabolism (5).

B. Impact of cognitive changes

Compliance to treatment needs appropriate cognitive capabilities to realise that a particular treatment is essential and crucial for wellbeing (29), which might be lacking in an adolescent living with a chronic illness. Early adolescents because of a lack in abstract thinking, experience difficulty adhering to treatment regimen. They are unable to plan ahead and prepare for various life situations and unable to foresee consequences. Prevention of long term complications is a weak motivator for adherence in this setting (30). Adherence in these conditions is maximal when the health care team partners with the adolescent in making decisions, giving due importance to health beliefs and personal goals of the adolescent (31).

C. Impact of the socialization process

Development of social interactions and self-image may be in contradiction to the treatment regimens (5). Orthopaedic and neuromuscular disabilities can impede interaction and so prevent development of social maturity. The extent to which these issues affect the disease management and outcome depends on how well an adolescent is able to balance priorities (32). We as Health Care Professionals have an important role in understanding and facilitating this balance.

Role of the Health Care Professional

Needs of adolescents living with a chronic illness are numerous. Health Care Professional in most of our Indian setting have less awareness about the psychosocial and economic factors that influence adherence in adolescents. With more recent researches and the available evidences in the literature, the awareness about these issues as major determinants of the clinical outcome is increasing among the health care teams (33). A holistic care approach isessential while taking care of this vulnerable group.

Aderence to medication in an adolescent with chronic illness

Hippocrates had described adolescent adherence by advising practising doctors in his times to "keep watch also on the fault of patients which often make them lie about the taking of things prescribed" (34).

Compliance is defined as 'the extent to which a person's behavior, in terms of taking medication, following diets or executing lifestyle changes, coincides with medical or health advice' (35). Kyngas et aldefined adherence as 'an active, intentional and responsible process of care, in which the individual works to maintain his or her health, in close collaboration with health care professional (36). Compliance, or adherence is defined as the degree to which a person's behaviour coincides with medical or health advice (37). Two frameworks on the concept of adherence are well known - one of which involves the interaction between the patient and the health care professional and a second that focuses on the patient's cognitive-motivational processes. Both these suggest compliance to be a dynamic process rather

than an outcome and that adherence is relative rather than absolute and has to be accepted according to its impact on treatment benefit rather than as deviation from prescribed treatment.

For adolescents living with chronic illness such compliance may involve adhering to a prescribed diet, medication and exercise regimens and attending regular follow up appointments. WHO estimates that, only 40- 50% of patients receiving medication for chronic illness are adherent (38). Rates of adherence drop after the initial six months of treatment.

In a meta-analysis including paediatric and adult populations, DiMatteo et al compared the outcome of illness among patients who adhered to treatment with those who did not, and found a 26% reduction in outcome among those who did not adhere. The odds of a good outcome if patient is adherent is three times more than the odds if the patient has low adherence (39).

Bender et al reported that only 50% to 60% of children were taking prescribed doses of inhaled medications. Murphy et al noted that out of 161 adolescents with HIV, 83% took ‘some’ of their medications, and only 50% reported adherence to the entire regimen (41).

Shemesh et al reported an ‘ideal adherence’ rate after liver transplant in children and teens, ranging from 51.9% to 70.4% (42). Very low adherence in teens has significant consequences for themselves, their families and the health care system. For an adolescent with chronic condition good adherence is essential in improving quality of life style and decreasing the morbidity and medical complications significantly. Adherence also avoids overuse of the health care system in terms of

hospital visits, hospital admissions, investigations and the total cost involved. Ho et al, demonstrated an approximate cost to savings ratio of 1:10, with improved self-management of chronic disease (43).

A study evaluating compliance to steroid therapy in patients less than 15 years of age noted none of the participants were entirely adherent to the prescribed medication (44).

A study amongst American adolescents reported an adherence to antiretroviral therapy of only 50 to 75% (45).

In another study amongst seropositive American adolescents between 12 and 19 years, identified the following factors for poor compliance to medications: forgetfulness, changes in the day to day activities, increased number of pills, the side effects associated with the drugs and depression (46).

Johnson et al analysed a group of adolescents with type I diabetes and reported that 25% were neglecting insulin, 81% were not sticking to their diet and 29% were not doing their home glucose monitoring but were just filling the dairy with false levels (47).

Adherence pattern in adolescents and the Ill effects of poor adherence

Adherence to treatment for chronic paediatric diseases is known to decrease over time (48, 49). Though poor adherence can be a notorious part of the normal adolescent's behavioural response, for an adolescent living with a chronic illness, it can have a significant detrimental effects on their health, life style and social wellbeing. The personal health beliefs model by Becker and Maiman states that adults are more likely to comply with treatment if they perceive themselves to be vulnerable

to an illness or to serious complications and if they anticipate benefits from treatment (50). There is no such link between beliefs and adherence identified for adolescents.

Most of the research on adherence often fails to consider these specialized needs of adolescents and their families, and to identify that some seemingly normal behaviour of an adolescent can lead to no adherence (482). Hence it is vital to understand chronically ill adolescents better and pay attention to their understanding of illness, their emotional make up and their specific concerns in order to enhance adherence. Adolescents with chronic illness might be on treatment regimen which includes both medication and life style changes. Such patients when they remain asymptomatic for long periods, lose motivation to continue the regimen, resulting in relapse.

Noncompliance results in poorer health outcomes, increased morbidity, poorer quality of life and at times can result in mortality. The cost involved with poor compliance can be enormous due to frequent emergency department visits, complication related treatments and generally the increased use of the health care resources. Studies have shown that over half of the emergency visits are related to poor compliance (51). When disease stability is difficult to achieve, in order to ensure treatment compliance, the efforts to promote compliance has to be as important as the treatment regimen (48). Health Care Professionals and parents need to be aware of these adherence pattern and the ill effects of non-adherence among their adolescent patients and work together to prevent one (48).

Assessment of non-adherence

Noncompliance is assessed using quantitative clinically measurable events, e.g. number of hospitalizations, weight gain and laboratory reports. Methods include chartreviews, self-report by patients and families, number of missed appointments, pill counts and electronic monitoring systems. Each of these methods has limitations. In subjective measures, data collection is easy but potential for recall bias is high. Objective measures are cumbersome. Objective measures such as drug assaysprovide data only on recent doses. In a clinical setting, self-reported measures remain the most practical tool to assess adherence. Objective measures should be used for validation (48).

Factors influencing adherence

Different factors that have a potential to impact on adherence have been studied, such as demographic, familial, socioeconomic, personal, type of illness, therapeutic regimens and relationship with Health Care Professionals which will be described in detail in the below paragraphs. Positive factors include a good family functioning, close friends, treatment with immediate benefits, parental and adolescent beliefs regarding severity of illness and efficacy of treatment and empathy from Health Care Professionals (30). Negative factors include older age of adolescent, mental health illness in the caregiver, family conflicts, complex therapy, medication with side effects and denial of illness. Adolescents who experience emotional, social, family or mental health problems have poor compliance. Other factors include perceptions of obstacles to adherence, attitudes toward therapeutic regimens, parental

influence and influence of other significant adults or peers, perception of the therapeutic regimen and the level of influence of these persons on the adolescent (30). WHO considers important the following five interacting factors that contribute to non-adherence (WHO 2003) (52):

1. Health care system/team factors
2. Patient related
3. Therapy related
4. Condition related
5. Social and economic factors

These factors are elaborated in the following paragraphs.

1. Health care system related factors:

An important factor is the interaction that occurs between Health Care Professionals and adolescent (53). In the west, adolescents with chronic illness attend clinic appointments more frequently than healthy peers. However, most of the time they receive suboptimal general and preventive care. The reason being that they are normally cared for by the primary care physicians than by the specialists who understand the disease dynamics better to enable a comprehensive treatment (27). Primary care including immunisation rates amongst adolescents with chronic illness are low when compared to the general population, for the same reasons (54) .In a study of 46 children and adolescents with cancer, compliers and non-compliers differed significantly in how better they comprehended the instructions that were given to them. 55% of those who had good compliance understood instructions whereas none of the non-compliers understood instructions given to them (55. Patient

who are compliant usually consider their treating physician friendly (56). It is essential that the health care team understand an adolescent patient's concerns and expectations in order to ensure compliance.

2. Treatment related factors:

Treatment related factors include physical and cosmetic side effects of medications, concerns regarding drug safety, dosing schedules that are confusing and difficult to maintain, a poor knowledge of disease process, its treatment and possible complications (57). Side effects of drugs is a major concern especially immunosuppression. Corticosteroids stunt growth, cause truncal obesity, acne, hirsutism, hypertension and osteoporosis. Such effects are aversive to the adolescent need to be physically strong and attractive and their desire to belong. Generally, adherence is better among adolescents who are prescribed fewer medications in smaller doses (58).

In a study, once and twice a day medications had compliances of 73% and 70% respectively compared to three or four times a day with 52% and42% respectively. Also the adherence tended to decrease over time in a chronic illness (59) Strict adherence can make patients feel unwell and upset because of side effects and dietary restrictions as with diabetes and renal failure treatment (48) Hence it is understandable that many of these adolescent patients have difficulty seeing past immediate side effects to the potential long term benefits of strict adherence. This might result in repeated noncompliance (60).

3. Family factors

Good family functioning and a family structure are associated with good adherence (61). Parental stress related to this transitional period adolescence is doubly so in the presence of a chronic illness (48). The illness renders a major psychosocial burden on the family. Stress is felt significantly at various points in time, at the time of diagnosis, during ongoing medical treatment, because of social disruption, stigma of the disease, being marginalised and doubt regarding future can be major challenges to both the social and emotional wellbeing of the family. Parents should be encouraged to foster a transition from parental care to self-care while maintaining a good level of adherence. For a healthy adolescent development to take place, parent child relationship should be interdependent rather than independent (51).

Family factors such as poor communication between adolescent and parents, frequent conflicts, too high or too low a level of parental involvement and familial stress due to other factors have all been associated with patterns of adherence and non-adherence (62-64). Understandably adolescents from troubled families form a vulnerable group and they develop poor adherence.

Studies reveal that a good family support is a vital factor in adherence and parental support independently predicts good compliance (48, 65).

A study conducted among adolescent asthma patients (mean age of 10 years) using inhaled beta agonists and corticosteroids showed a significant noncompliance associated with lesser knowledge about disease and family dysfunction. This further emphasises the role of family determining adherence (66).

Anderson et al in a cross sectional study among 89 diabetic patients (10–15 years), reported better compliance and better glycaemic control with increased parental involvement in the management.

4. Psychological factors:

Chronic illness in adolescence represents a major psychosocial burden to the individual and the family. They face problems related to adjustment to physical changes, sexual awakening, establishing identity and peer group involvement, need for independence, abstract reasoning and planning for the future. An overall inability leads to noncompliance and mood disturbances. It is imperative that Health Care Professional try to understand chronically ill adolescents and be mindful of their concerns and emotions with regard to adherence

Chronic illness in an adolescent causes a sense of helplessness and anger as they might not be able to take control of themselves. Conflicts about autonomy within family and inability to have a normal developmental like peers may also result in noncompliance (51). Adolescents living with chronic illness like said earlier are at an increased risk for mental health and adjustment issues (67). Psychological comorbidity is 20%, twice that of healthy young people in the US (68). Vessey in this study suggested that social roles are disrupted, which is a common feature for all chronic diseases.

Studies done in adolescents with Diabetes Mellitus have shown that the poor glycaemic control (69) and a low turnover to follow up visits have an associated psychological factor (70) Another longitudinal cohort study done by Kathyrn et al

showed that poor glycaemic control is observed in a significant number of the adolescents in spite of a well organised individualized diabetic care strongly supported by the treating team. In this study the poor treatment control was seen secondary to the psychological and behavioural problems they experience during this transition period to adulthood (71).

Chronic conditions were earlier assumed to be protective against impulsive behaviours by restricting them from getting involved in high risk behaviour. This is refuted by research indicating that "young people with a chronic condition are not less likely to undertake risk behaviours than their healthy peers" (72). These behaviours increase adverse health outcomes. E.g. with smoking habit, in adolescents with asthma, there is risk for increased pulmonary deterioration; those with sickle-cell disease are at increased risk of acute chest syndrome. Use of tobacco accelerates cardiovascular complications, alcohol increases the degree of hepatotoxicity associated with hepatotoxic drugs used in the treatment of many chronic autoimmune conditions. It is therefore essential to prevent adolescent high risk behaviour especially when they have a chronic illness.

Studies demonstrate an association between physical and psychiatric disorders among adolescents. Rosina et al noted that adolescent girls with chronic illness were more anxious, depressed and withdrawn than those without a chronic illness; and this correlated well with poor compliance (73).

Treatment regimens per se can evoke psychological symptoms. These require prompt treatment to prevent noncompliance and a further major psychiatric disorder.

For example, depression can result in decreased energy, sense of hopelessness or impairment in cognitive functioning and therefore affect adherence.

5. Social factors

School plays a pivotal role in the lives of most adolescents, whether they are healthy or chronically ill. Beyond the scholastic role, school serves as a ground for interaction with peers, development of social skills and establishing identity. School absenteeism can negatively affect these aspects (51). Different diseases cause varying degrees of school absenteeism. Missing school can prevent a teen from keeping up with school work, cause poor academic performance and failure. This in turn poses an immense burden on adolescents who are already struggling with the reality of a chronic illness. Poor scholastic performance during adolescence are shown to be associated with lower self-esteem in adult survivors of chronic disease (51).

Some of the Interventions to improve adherence

When Health Care Professional understand the factors contributing to poor adherence, adherence enhancing interventions can be implemented. A comprehensive chronic care model designed by Wagner and colleagues, has revealed factors that can improve adherence and clinical outcome in the presence of a chronic illness. The cardinal feature in this model includes a smooth functioning and interaction between the health-care system and the families. This model presents a “prepared proactive practice team” and an “informed, activated patient team” (74).

Health care related factors

For an effective adolescent oriented intervention, Health care Professionals should anticipate the adolescent's poor compliance and promote their autonomy and decision-making in management (51).

Adherence is better when instructions for taking medication are given clearly and understood well by the patient (53). Adherence has been reported to be better when visits to the physician are longer and more frequent (75). The attitude and interest from the HCP with regard to patient's wellbeing seems to improve compliance (76).

Studies emphasise the need to interact with the entire family at the time of initial diagnosis of a chronic illness, to render a clear explanation about disease, associated complications, need for a compliant long term follow-up and adherence to the treatment and overall health advice. Such strategies result in a good clinical outcome. This builds a good rapport between the treating team and patient which will serve to improve compliance (51).

Thus the medical team involved in the care of an adolescent with a chronic illness should be:

1. Able to identify unexplained medical symptoms without significant associated organic factors, non-compliance with medical treatment, school refusal and substance abuse. Presence of these needs further exploration to look for psychosocial stressors (51)

2. When non-adherence is suspected, the treating team should meet with patient and family to identify problems in family dynamics (51).
3. A multidisciplinary approach a social worker, nurse, pharmacist, and others can enhance compliance by strategies like written information about drugs and doses, timings, sending reminders for medication and outpatient appointments and help in identifying side effects.
4. To make them participate in treatment planning. They should be motivatedto share in the decision-making and encouraged to exercise authority and independence as a member of the team. This will enable an autonomy which is otherwise prevented by the disease itself (48).

Medication related factors

Treatment regimen can be simplified by using medications with a longer half-life, simpler dosing regimens with a better side effect profile.

It is essential for an adolescent patient to understand the need for the medications and the pharmacodynamics of medications. This should be encouraged by the treating team by educating them and providing them with simple, clear instructions. Before they leave the hospital, they can be asked to repeat what was advised so that misinterpretations can be sorted out immediately.

Since forgetfulness remains as one of the most common cause for noncompliance; reminders techniques can be taught to the adolescents to improve their adherence to treatment (77) which the adolescents can be taught about. Reminder techniques like alarms, pill boxes, using diaries or logs, SMS/email reminders can be introduced to them used. Since electronic reminders and tele monitoring are being

used increasingly these days, these modern techniques can also be advised to adolescents who can use them (78).

Family related factors

Gage et al conducted a systematic review of education, self-management, psychological or combinations of these factors' influence in adolescents with type 1 diabetes mellitus. Nearly all sixty-two studies they had reviewed reported parental involvement as main positive factor in improving outcome (79).

Parental involvement was proved to increase compliance and diabetic control, in a cross-sectional study by Anderson et al, among 89 adolescents (10–15 years old). Involvement of the family as a whole is essential when we anticipate poor compliance in these patients.

For families to become a good support system in increasing compliance in adolescents with chronic illness some of the following steps may be considered:

(1) Linking up adolescents with chronic illness and their families with other similar families and support groups can be an encouragement to each other in the treatment process and can enable good adherence.

(2) During their medical visits with the adolescents, families can be encouraged to provide emotional and physical support.

(3) Strategies to improve family communication and coping skills can be taught to the family members and wherever needed family therapy can be used to enhance compliance (48).

(4) Families can also be motivated to give positive feedback and regular, tangible rewards for adherence related behaviours to the adolescent.

(5) Ongoing education in the form of frequent gathering for similar families to enable them to understand disease, medication and more importantly the need to understand their role in ensuring adherence by providing adequate monitoring and support for the adolescent can be organised by the treating health care team (48).

Psychological factors

Recent research has focused on social and emotional resilience in spite of their struggles, in adolescents with chronic illness (2). Both the family and treating medical team should recognise this potential and encourage and reinforce them to adopt their own strategies. They should be motivated to participate in decision-making, to exercise their authority and independence as patient member of the team. This in turn will reinstate their autonomy.

Social factors

Most adolescents want to attend school, despite their illness, to meet with their friends, unless psychosocial factors in adolescent and their family inhibit them. Due to the presence of the chronic illness, an adolescent can experience a comprised life in the social front. This greatly will interfere with their school performance, peer interaction and their social development. A fear of a social stigma or discrimination can prevent the adolescent from mingling well with the peer group. Studies have shown that an adolescent who has a good social support system exhibits a good

adherence to medication. Hence it is essential to create a good social support system for the adolescent with a chronic disease to promote good adherence.

Qualitative research

Qualitative research is an important form of research methodology which helps in understanding beliefs, attitudes and outlook of patients towards health and the health care system. In contrast to quantitative research, which ventures to prove a hypothesis, qualitative research relies on interpretation of data collected from personal interactions with participants. It enables understanding of emotions and perspectives of participants regarding a particular research question (80).

Qualitative methodology reveals a clearer and more extensive description of the fears and problems encountered by patients when ill. Such a clear perception of the state of illness and treatment cannot be gathered from a quantitative research. Qualitative research also helps to comprehend and appreciate the complexity of health care related psychological and socio economic needs of patients. It enables understanding of health related beliefs and attitudes of patients and their families. Qualitative methodology produces themes and concepts that provide ground data for future research in that particular area. The participant responses to semi structured questions are ideal for creating concepts that are completely new and are an eye opener to several unreached facets of patient difficulties (81).

Qualitative research on compliance reports new beliefs and attitudes that explain reasons for poor compliance and high burden of morbidity associated with such compliance. Some of the common types of study designs in qualitative research include (82):

1. Phenomenology

It is done to explore patient's experiences with regard to disease or a situation. From the raw data obtained from the conversations of the participant, themes are identified by the researcher which are then analysed to understand their experiences. These themes impart insights into notions underlying the transformative learning theory (Ashe, Taylor, & Dubouloz, 2005)

2. Ethnography

This form of qualitative research is used to explore cultural aspects of the study group such as the living conditions, cultural beliefs and their social patterns. It can also be used to study the culture and beliefs of organisations, or a group of people dealing with a particular social issue. In health care sector, ethnography began in the late 20th century as a strategy to analyse the impact of illness on study participants (82).

4. Grounded Theory

Grounded theory aims at constructing a theory to explain the core social processes in a given situation. It begins with collecting data using any of the qualitative research methods. As data is collected, core issues are identified. This initial phase of research can take a longer duration. When data collection is complete the investigator is more engaged in analytical strategies and summary.

There are multiple key analytic strategies such as:

Coding – Open coding is the first step. Line by line repeated ideas in the data are identified and labelled. Following this, in Axial coding open codes are refined and labelled into larger thematic categories, which describe the responses to each of the questions used. Then the final Selective/Theoretical coding is done by identifying relations among the various categories. In conclusion, a final theoretical model is generated. In my qualitative analysis, we have used the coding system as mentioned in this.

Memoing - It is a process by which the investigator keeps recording thoughts and ideas as the study evolves. In most of the situations, early in the research these memos tend to be very broad while later as research progresses, it tend to be more focussed into a core concept.

Integrative diagrams and session are used to bring all the detail together, to help make sense of the data with respect to the emerging theory. This is best used in the group sessions where different members of the investigating team are able to interact and share ideas to increase insight (83).

4. Participatory action research (PAR)

PAR design involves the participants analysing their own personal socio cultural settings and experiences. They are encouraged to focus on group values, needs and goals needed to improve group outcome. Here the researcher works hand in hand with participants.

Qualitative research methods

Some of the commonly used qualitative research methods are:

1. Participant observation

In this the researcher rather than being an overseer, observes participants within the research setting and documents 'field notes' of all observations. This design is also called "field work". This method is employed when the aim is to observe how activities and interactions within a given setting give meaning to beliefs or behaviours. It is the method of choice when the situation or problem of interest is obscured from the knowledge of general public and the researcher tries to bring it to the light of everyone. It is time consuming process (82).

2. Personal interviews

In this method, both verbal conversation and non-verbal behaviours during the interview are recorded and these form the data. Key informant interview is a type of interview where the participant chosen has an important or different view point, an important status in that particular culture or a particularly sound knowledge about the subject. Emphasis is placed on careful recording of the dialogue between researcher and participant by audio recording followed by analysing the data and interpretation of the data. Open-ended questions are organised prior to interview, in order to extract the most needed information during the limited time. This method is less time consuming and less expensive.

3. Document Review

This is used in historical research, which studies how past events in the history and all the intentions behind each of them attributed to ancient culture and belief meaning and value. It involves in-depth learning to analyse texts, such as diaries, media reports or blogs. It is time consuming but productive.

4. Focus Group Discussion (FGD)

In this method, a group of participants are brought together in one place and asked to discuss a topic of. The researcher facilitates the discussion using a set of key questions to start and maintain a flow of conversation. The principles of FGD are similar to individual interviews. It is useful when multiple opinions are expected to understand a subject. Participants build on each other's opinion resulting in a meaningful in depth discussion on a specific topic. Multiple responses are gathered in a short time unlike in individual interviews. Researcher also observes the nonverbal communication of participants which is also data. A drawback in FGD is the constraints an individual might feel in expressing their views in a group setting. An important challenge while conducting an FGD is trying to ensure that both less talkative and the loud participants have equal opportunities to express their opinions.

A major advantage is that it enables observation of a larger interaction between participants in a very short period of time. Other salient features of FGD are

(a) ability to gather information on a larger range of behaviours

(b) greater variety of interactions with the study participants

(c) more open discussion of the research topic.

Focus Group Discussion among adolescents with chronic illness

Several Focus Group Discussion have been conducted in the past among adolescents with chronic illness. An FGD was conducted among children and adolescents with bronchial asthma to study the reasons for poor adherence. Participants gave detailed descriptions of their asthma experiences, barriers to medications and also suggested strategies to improve adherence. They spoke about how their interactions with peers was affected, about medication annoyances and all other difficulties they experienced in going through a sick period (84).

Adherence to highly active anti-retroviral therapy (HAART) is poor among adolescents with HIV / AIDS. An FGD was conducted among twenty five adolescents attending a primary care facility, to assess adherence rate and explore their particular difficulties while taking medications. Their discussion provided descriptions of challenges in facing the HIV stigma and difficulties they encounter in taking medicines regularly. Half the participants missed medications because of fear of their disease getting revealed by friends and family. This study enabled researchers to understand how stigma of HIV affected the lives of the adolescent patients in various aspects, which eventually affected adherence (85).

A qualitative research was conducted among 8 adolescents with HIV, to explore the psychological and social problems faced by them. Participants shared their personal experiences and difficulties they encountered because of the illness. Content analysis of these interviews showed four themes: disclosing their status to others, medication adherence, relationships and psychological burden. Results of this study

emphasised the significant barriers that adolescents with HIV faced, preventing them from leading a normal life in society (86).

There are various studies published in several countries to identify adherence patterns in adolescents living with chronic illness, but there are no such studies published from India especially using Focus Group Discussion.

Qualitative analysis on adherence to chronic illness in India

There is very limited published data available on this matter from within our country. Some studies that have used qualitative methods to analyze adherence are listed below, mostly carried out in adult population. Qualitative study was done to analyse the barriers and promoters of HAART among 60 adults. There were49 men, 11 women; 33 taking the treatment, 27 who are not currently taking ART. This was conducted among patients receiving HIV primary care at an NGO based in Chennai, India. Trained ethnographers conducted in-depth interviews in Tamil. The conversations were then analysed for content and ethnographic data. All of the participants enclosed the cost involved in the treatment as a major barrier. Various other data obtained during this study highlighted the importance of reducing the cost of ART, family involvement in HIV care and also the need for frequent counselling to overcome psychological trauma associated with the stigma of living with HIV (87).

Modified Morisky adherence scale

Morisky Medication Adherence Scale is an eight-item self-assessment scale instrument that was initially designed to assess adherence to anti-hypertensive medication (88). It comprises of eight items: the initial seven items are scored

dichotomously and the last item on a 5-point Likert scale (0–1). The higher the score, the better the adherence. In the original cohort, Morisky et al classified scores of less than 6 as low, 6- 7 as medium and 8 as high adherence. MMAS-8 scale is also a valid instrument for evaluating medication adherence in patients with Inflammatory Bowel Disease and it has become the first ever medication scale to be validated in IBD (88). Children and adolescents with sickle cell disease (n = 75) were included in a study on adherence to medication, using Visual analogue scale and modified morisky score. This study suggested Modified Morisky Scale can be used to identify children/adolescents at high risk for poor response because of non-adherence. In our study we have assessed the adherence to chronic illness using the MMAS 8 score. This score has not been used in our country for adherence assessment in adolescents

MATERIALS AND METHODS

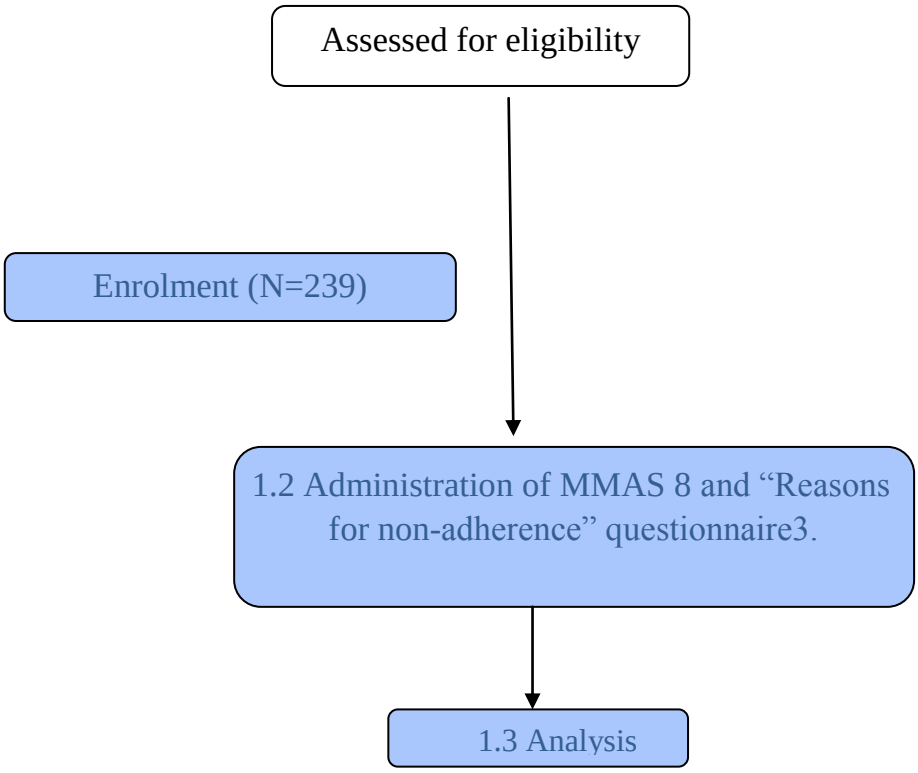
5. MATERIALS AND METHODS

Our study both included a qualitative and a quantitative analysis. The study was conducted after the approval by the Institutional Review Board of Christian Medical College, Vellore.)

Quantitative analysis

This part of the study was conducted with the use of a validated Modified Morisky Adherence Score to assess the adherence rate in the adolescents with chronic illness who attend our speciality OPD from November 2015 – June 2016. Participants were assessed for the eligibility and then if they fulfilled the criteria, they were included in the study after obtaining the parents' consent and adolescent's assent. MMAS questionnaire was self-administered followed by the 2nd part of the questionnaire which assessed the factors that were influencing adherence to medication in adolescents with chronic illness.

Detailed diagrammatic Algorithm of the study



Inclusion criteria for the study

1 Adolescents (10 to 19 years of age) who were diagnosed with a chronic illness and are on treatment from CMC for at least 6 months duration

Exclusion criteria for the study

1. Adolescents who are intellectually challenged to participate in a self administered questionnaire survey
2. Adolescents with hematological and various other malignancies receiving chemotherapy/radiotherapy
3. Filling of incomplete questionnaire

240 adolescents participated in the study and 239 of them had completed the Performa completely and one participant had not completed the study who was excluded from the data analysis

Qualitative Analysis

Methodology:

The second part ofthis study is a qualitative research among adolescents living with chronic illness. This study was conducted to explore factors affecting adherence, to understand their experiences in particular the impact a chronic conditionon their lives.

Sampling:

Adolescents 10-19 years old, were identified from those who participated in the quantitative survey and who attended sub specialty outpatient clinics from the paediatric endocrinology and paediatric respiratory units. Three focus groups were thus collected with each group ranging from 3-6 per group.There was a mixture of adolescents in that, one group had adolescents with different types of chronic illness.

The procedure:

Participants identified were invited to take part in the FGD. The group comprised of patients from Vellore town. Informed consent from parents and a verbal assent from adolescents was obtained prior to the FGD. All the discussions of the group discussions were audio taped after obtaining authorization from the participants.

Two investigators were involved in each FGD. Participants were reminded the previous day about the session. Before the start of the session, the participants were briefed about how the session will be conducted. They were encouraged to speak up loud and clear without reservations regarding all their views to a particular question. They were gathered in department conference room in the hospital building. One investigator facilitated discussions using a list of questions from a preformed semi structured questionnaire. The second investigator audiotaped the whole session and took notes to indicate which participant was saying a particular part and writing nonverbal communication which seemed important. Equal opportunity was given every participant. This was done by first presenting a question and ensuring that every participant had spoken their views. Only after all of them had responded would the facilitator move to the next question.

Data collection:

Each FGD lasted an hour. The sessions were organised in the Child Health Conference room in the hospital building after obtaining prior permission. The sessions were conducted in Tamil, the mother tongue for all the participants. Discussions were continued till a point of saturation was reached.

The audio recorded sessions were transcribed verbatim in Tamil with quotes and emotions written attached to the opinions in Tamil. The Tamil transcription was then translated to English and then back translated into Tamil according to protocol to ensure validity.

RESULTS

6. RESULTS

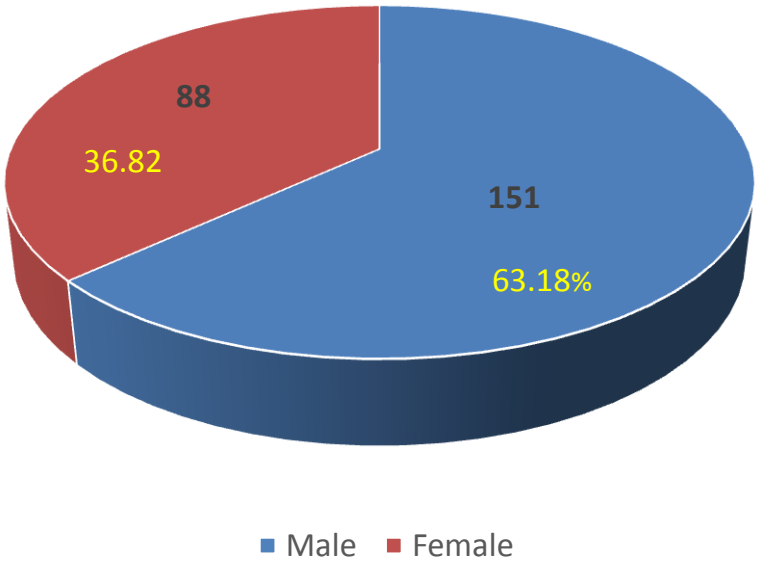
QUANTITATIVE RESEARCH

After a detailed explanation and obtaining informed consent from parents and a verbal assent from the patients, 239 adolescents with chronic illness were included in the study based on inclusion criteria. This study was carried out from November 2015 to June 2016.

DEMOGRAPHY OF STUDY POPULATION

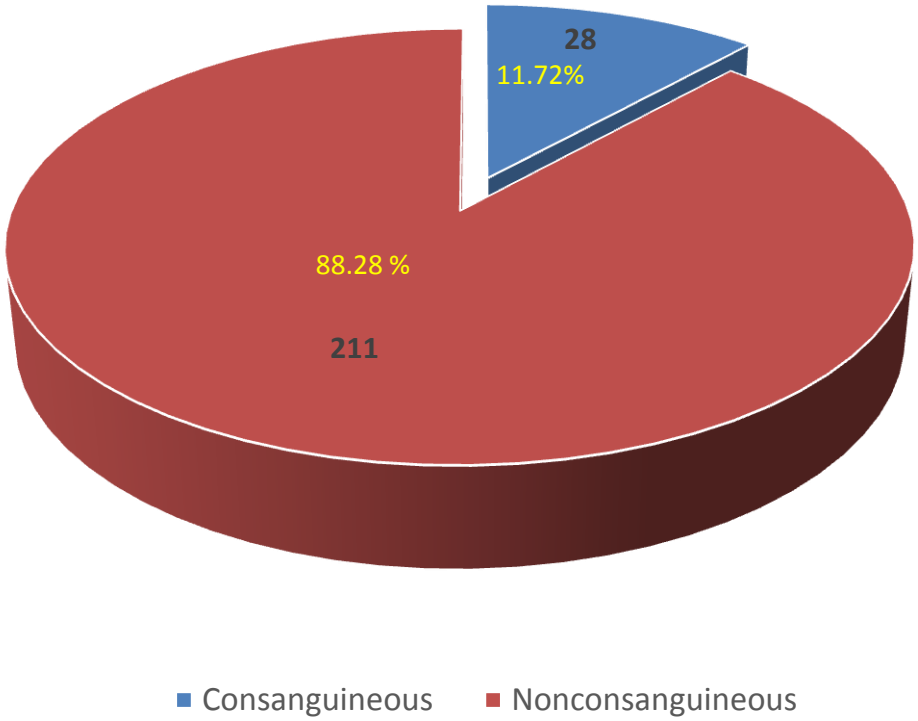
The baseline demographic characteristics of the patients are described below.

Fig 1. Gender distribution



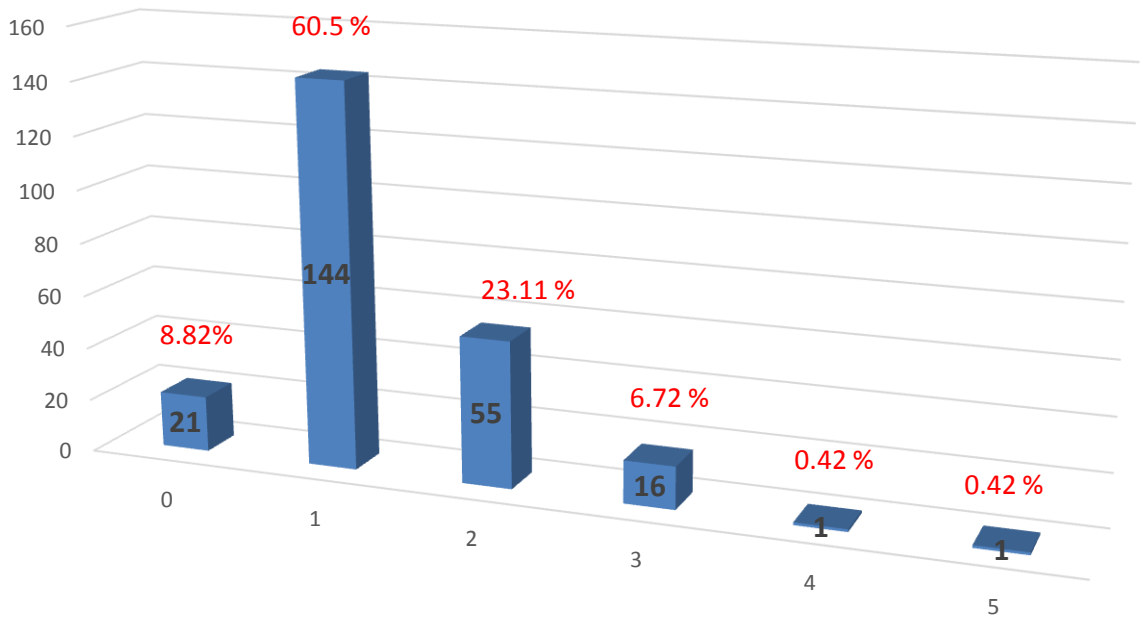
Of the 239 patients, 151 were boys and 88 girls.

Fig 2. Consanguinity



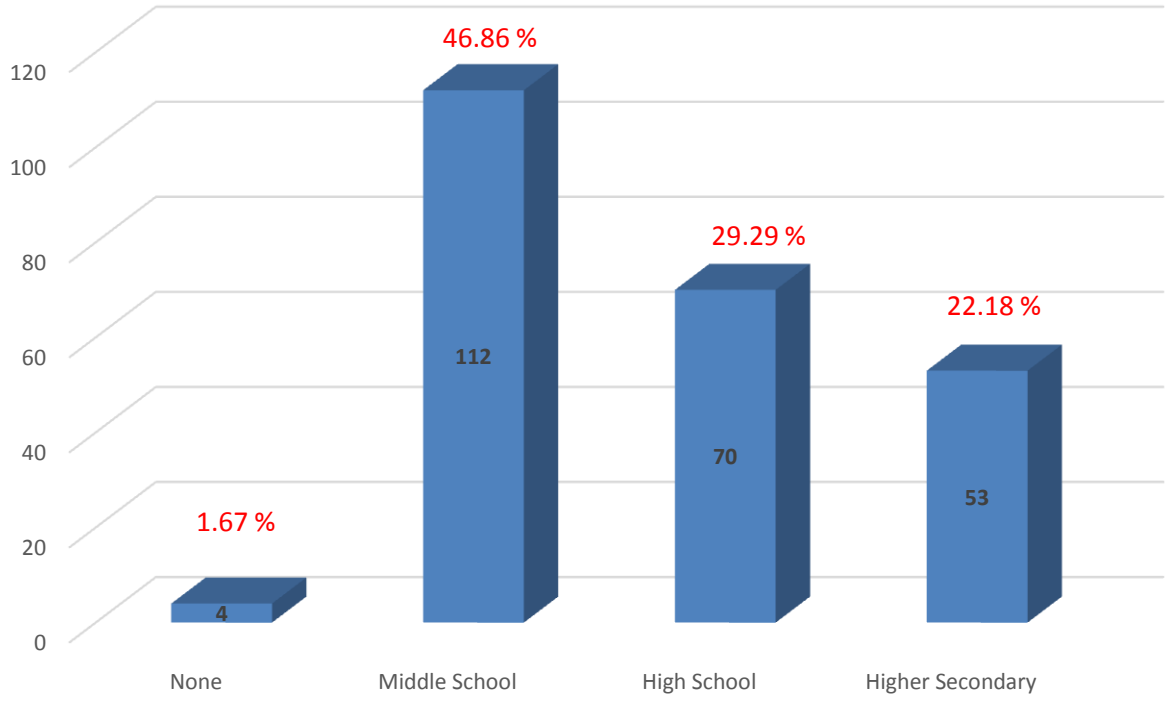
Of the 239 adolescents, 28 (11.72%) had consanguineous parents.

Fig 3. Siblings



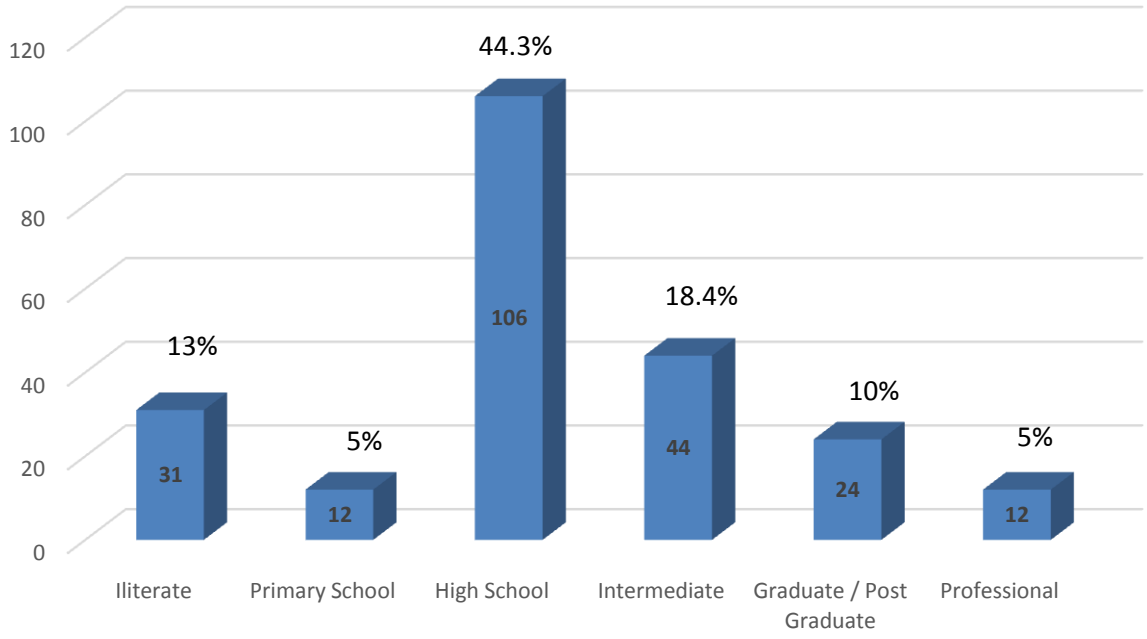
60.5% of the patients had 1 sibling; 23.11% had 2 siblings.

Fig 4. Education of adolescents



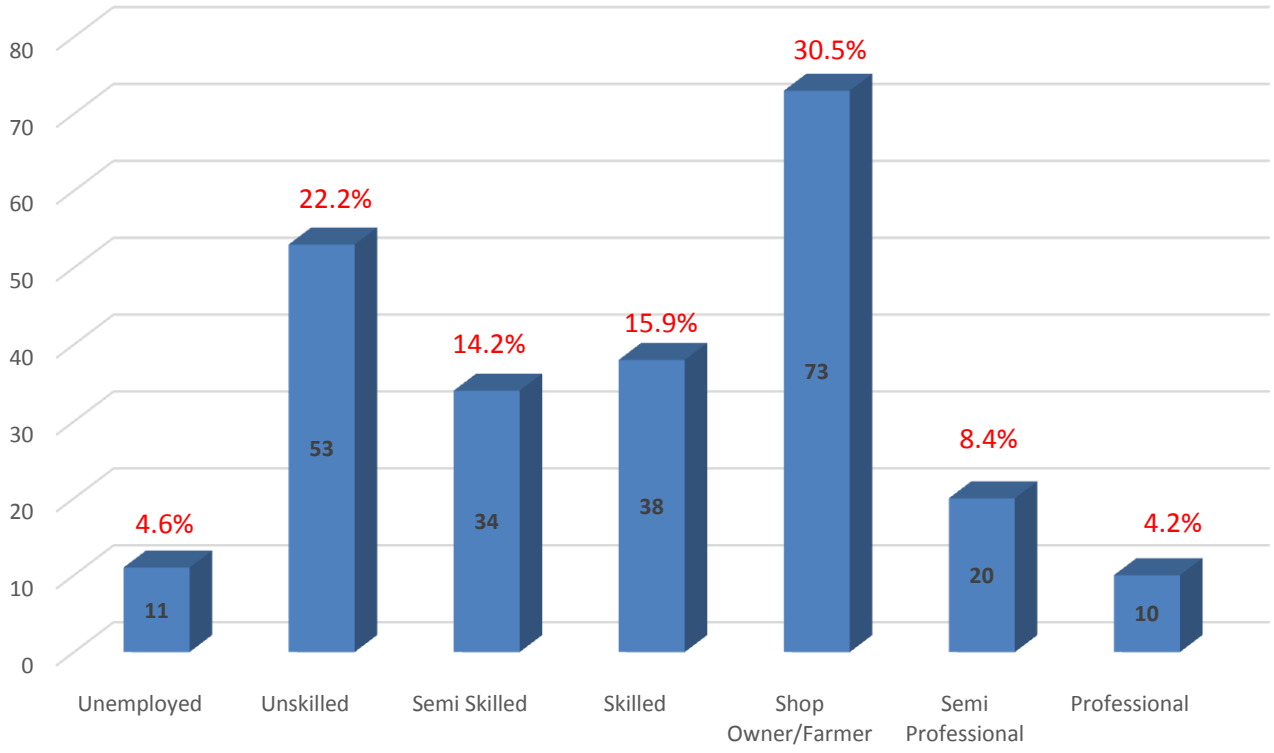
46.86% of the adolescents were in middle school (class 5 to 8) ; 29.9% in high school (9^{th} and 10^{th} class), 22.18% in higher secondary (11^{th} and 12^{th} class) and 1.67% were not going to school.

Fig 5. Educational status of parent



44.3% of the parents had graduated from high school. 13% were not literate. 5% were professionals.

Fig 6. Occupation of parent



12.6% of the parents were semi-professional or professional, 52.3% were skilled / semi-skilled or unskilled workers, 30% were shop owner / farmers and 4.6% were unemployed.

Table.1 : Gender Vs Adherence :

Gender	Low adherence		Good adherence		
	n	%	n	%	
Boys	64	42	87	58	**p = 0.567**
Girls	29	33	59	67	

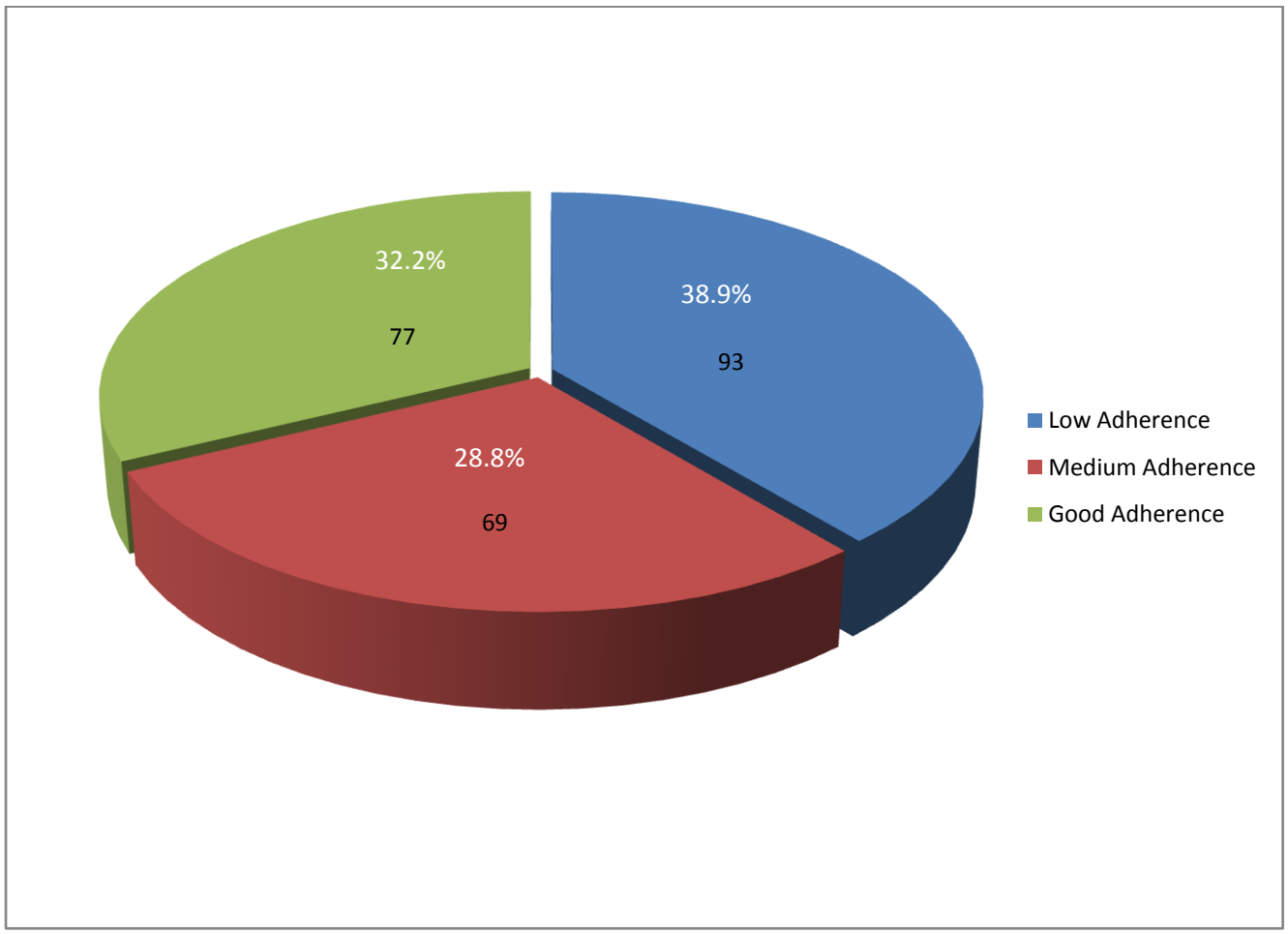
Among boys, 58% had good adherence and among girls 67% had good adherence.

Table. 2 : Adherence based on socioeconomic status

Socioeconomic Status	Low adherence		Good adherence		
	n	%	n	%	
Lower class	47	41	67	59	
Middle class	45	39	71	61	**p = 0.204**
Upper class	1	11	8	89	

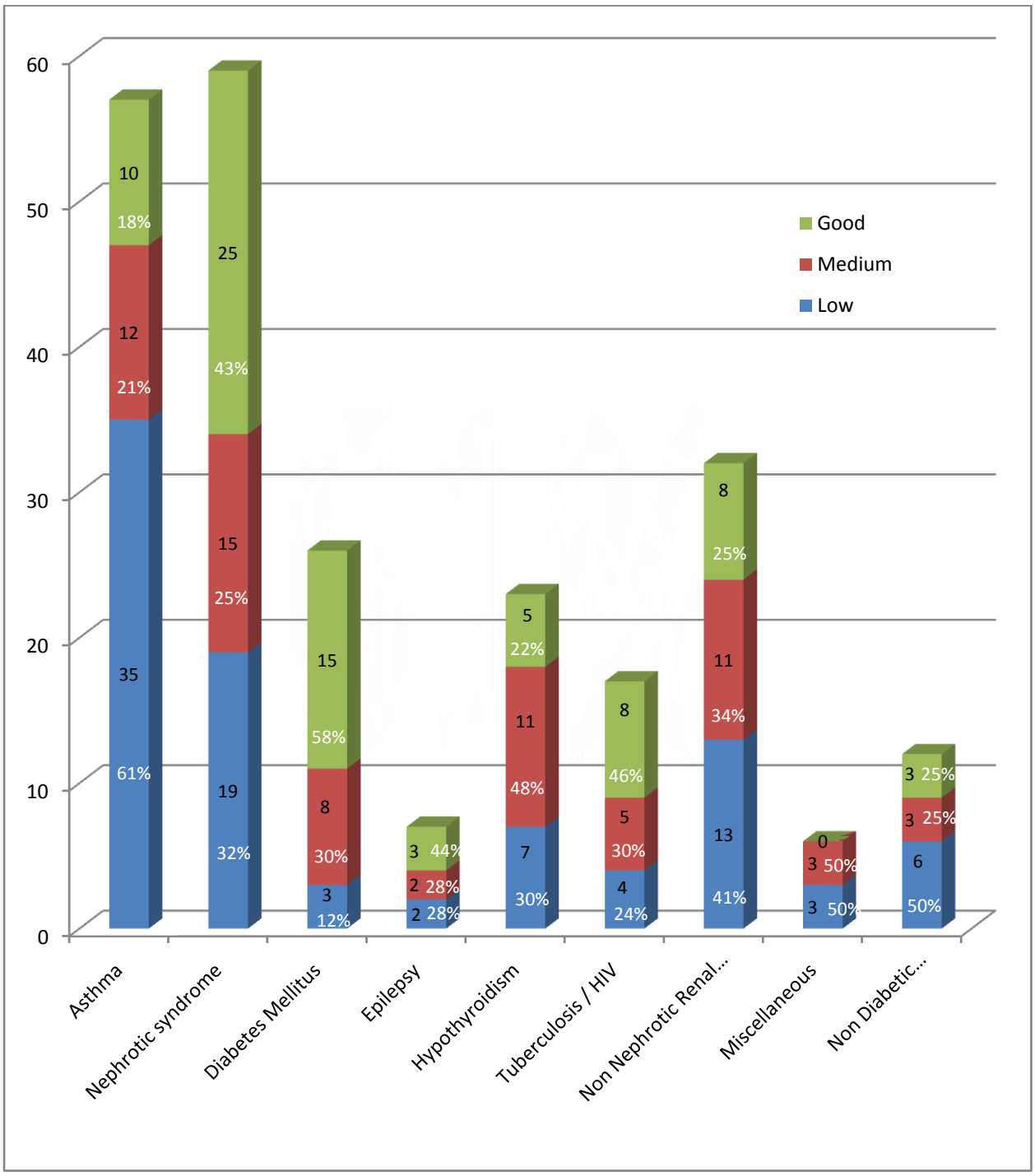
Good adherence was present in 59% of those in low SES, 61% in middles SES and 89% in the upper class.

Fig 7. Adherence to treatment



Overall 32.2% had good adherence, 28.8% medium adherence and 38.9% poor adherence.

Fig 8. Disease wise rates of adherence



This bar diagram explains the percentage distribution of adherence level amongst different chronic illness.

58% of those with diabetes had good adherence, 43% with nephrotic syndrome had good adherence. 44% with epilepsy had good adherence, 46% with TB / HIV had good adherence. 61% of patients with asthma had poor adherence.

The second part of questionnaire

Responses with medium and good adherence based on MMAS scale were combined together as good adherence. Responses never and seldom to the 2nd part of questionnaire were combined together as seldom. Responses as usually, frequently and almost always were combined together as "usually". Responses to each of the questions were then compared with adherence level based on the MMAS score. Following were the observations made.

MEDICATION RELATED FACTORS AFFECTING ADHERENCE

Table 3 : Difficulty taking pills vs Adherence

Difficulties in taking pills	**Low adherence**		**Good adherence**		
	N = 93	**%**	**N = 146**	**%**	
Seldom	53	31 %	117	69 %	**p = 0.0002**
Usually	40	58%	29	42%	

Of those who had seldom any difficulty in taking the pills, 69% had good adherence. 42% of those who usually had difficulty taking the pills had good adherence.

Table 4: Reminders vs. Adherence

Needs reminders to take medications	**Low adherence n (%)**	**Good adherence n (%)**	
Seldom	28 (29%)	70 (71%)	**p = 0.007**
Usually	65 (46%)	76 (54%)	

Of those who seldom needed a reminder to take medication 71% had good adherence. 54% of those who usually needed a reminder had good adherence

Table 5: Missing medications Vs Adherence

Missing medicines	**Low adherence**		**Good adherence**		
	N = 93	**%**	**N = 146**	**%**	
Seldom	72	33.48%	143	66.5%	**p =< 0.0001**
Usually	21	87.5%	3	12.5%	

Among those who seldom missed their medicines , 66.5% had good adherence and it was 12.5% in those who usually missed their medicines

Table 6 : Understanding complications of non complicance Vs Adherence

Understanding the complications of non adherence to treatment	**Low adherence**		**Good adherence**		
	N = 93	**%**	**N = 146**	**%**	
Seldom	40	46%	47	54%	**p = 0.099**
Usually	53	35%	99	65%	

Among those who seldom understood the complications of non adherence to treatment, 54% had good adherence and amongst those who usually understood the complications of non adherence to treatment, 65% had good adherence.

Table 7 : Anxiety about side effects Vs Adherence

Worry about the side effects	**Low adherence**		**Good adherence**		
	N = 93	**%**	**N = 146**	**%**	
Seldom	85	42%	119	58%	**p = 0.039**
Usually	8	23%	27	77%	

Among those who seldom worried about side effects of medications , 58% had good adherence. Among those who usually worry about side effects 77% had good adherence**.**

Table 8 : Complexity of treatment Vs Adherence

Complexity of treatment regimen	**Low adherence**		**Good adherence**		
	N = 93	**%**	**N = 146**	**%**	
Seldom	74	37%	128	63%	**p = 0.101**
Usually	19	51%	18	49%	

Among those who seldom felt that their medication was complex ,65% had good adherence. Whereas those who usually felt that their medication was complex , 49% had good adherence.

HEALTH CARE TEAM RELATED FACTORS AFFECTING ADHERENCE

Table 9 : Trust in your doctor vs Adherence

Trust in your doctor	**Low adherence**		**Good adherence**		
	N = 93	**%**	**N = 146**	**%**	
Seldom	1	100%	0	0	**p = 0.389**
Usually	92	38%	146	62%	

Among those who said they usually trusted their doctor, 62%had good adherence.

Table 10 : Trust in health care team vs Adherence

Trust in the health care team	Low adherence		Good adherence		
	N = 93	%	N = 146	%	
Seldom	2	100%	0	0	**p = 0.150**
Usually	91	39%	146	61%	

Of those who trusted in the health care team , 61% had good adherence.

Table 11 : Encouragement by the health care team vs Adherence

Encouragement by the health care team	Low adherence		Good adherence		
	N = 93	%	N = 146	%	
Seldom	0	0	1	100%	
Usually	93	39%	145	61%	**p= 0.823**

Of those who were usually motivated by the health care team ,61% had good adherence.

Table 12 : Knowledge about the disease vs Adherence

Knowledge about the disease	**Low adherence**		**Good adherence**		
	N = 93	**%**	**N = 146**	**%**	
Seldom	5	34%	10	66%	**p = 0.787**
Usually	88	40%	136	60%	

Of those who seldom had knowledge about their disease , 66% had good adherence .And amongst those who usually had knowledge about their disease , 60% had good adherence.

Table 13 : Clarifying regarding treatment vs Adherence

Clarification of doubts	**Low adherence**		**Good adherence**		
	N = 93	**%**	**N = 146**	%	
Seldom	11	40%	17	60%	**p = 0.966**
Usually	82	39%	129	61%	

Of those who seldom clarified their doubts , 60% had good adherence .And amongst those who usually clarified their doubts , 61% had good adherence.

SOCIO ECONOMIC RELATED FACTORS AFFECTING ADHERENCE

Table 14 : Treatment related financial ability vsAdherence

Management of financial needs	**Low adherence**		**Good adherence**		
	N = 93	**%**	**N = 146**	**%**	
Seldom	17	50%	17	50%	**p = 0.184**
Usually	76	37%	129	63%	

Of those who seldom had financial difficulties , 50% had good adherence .And amongst those who usually had financial difficulties , 63% had good adherence.

Table 15: Ability for routine activity vs Adherence

Attending regular activities	**Low adherence**		**Good adherence**		
	N = 93	**%**	**N = 146**	%	
Seldom	5	34%	10	66%	
Usually	88	40%	136	60%	**p = 0.782**

Of those who seldom were able to attend to their regular activities, 66% had good adherence .And amongst those who usually attend to their regular activities 60% had good adherence.

PSYCHOLOGICAL PROBLEMSAFFECTING ADHERENCE

Table 16: Sadness regarding disease vs Adherence

Feeling sad about the disease	Low adherence		Good adherence		
	N = 93	%	N = 146	%	
Seldom	14	30%	34	70%	p = 0.138
Usually	79	41%	112	59%	

Of those who seldom felt sad about their disease ,70% had good adherence .And amongst those who usually felt sad about their disease , 59 % had good adherence.

Table 17 : Sharing treatment related difficulties with family & friends Vs Adherence

Sharing of medication related difficulties	Low adherence		Good adherence		
	N = 93	%	N = 146	%	
Seldom	32	34%	61	66%	**p = 0.276**
Usually	61	42 %	84	58%	

Of those who seldom shared about their treatment difficulties, 66% had good adherence. Amongst those who usually shared about their treatment difficulties, 58% had good adherence.

QUALITATIVE ANALYSIS

Data analysis:

The transcribed raw data was analysed using grounded theory format. Quotes from each of the 3 FGDs was initially arranged in a sequential order. This sequence was based on the responses to each of the open ended question asked during the FGD. Then the quotes were coded using different colours in Microsoft word document for each response. Then focused coding was derived by using the initial codes. From focussed codes, interpretation of the qualitative data was made.

RESULTS AND DISCUSSION

After analysing the responses that were obtained during the group discussions using the grounded theory format, the following were the results obtained. The participants after an initial hesitation, were very enthusiastic in speaking. They had a lot of differing views. And they also seemed to listen carefully to other participants and either agreed with or refuted other statements.

Age and sex distribution of participants:

The mean age of the participant was 12.5 years and 60% of the participants were male and 40% were female.

Some of the factors that influenced adherence brought out during the focus group discussion is as follows

Health care associated factors:

1. **Understanding their illness pattern and process:**

It was observed that even though the participants are young people, they seem to be having a fair knowledge about their disease – the cause, the clinical manifestations, aggravating factors, complications associated.

"They have told me that since pancreas is not secreting insulin, I have got the disease"(diabetes mellitus, girl 12yrs)

"They have told me not to play much. If I play so much my sugars can fall down and I can get fits. I should follow the correct diet doctors have told me. And I have to do my exercises regularly"

"They told it is a problem with the pancreas, so if it doesnot work well, the blood sugar will go up"

"They have told me that we can get wheezing from our relatives. They told if we eat cold items then we can get wheezing from that;and if we walk in cold weather we can get wheezing"(asthma)

"They told me I have lung problem which gets irritated frequently. As a result of which I develop wheezing"

"They have told me that protein is wasted in my urine. They have told me not to add any extra salt"(nephrotic syndrome)

"They have told me once when my sugar is under control, I don't have to come frequently. But have to continue the medicines lifelong"

"They have told me that the blood sugar should always be normal. Told me not to eat sweets, to follow regular diet, do yoga, walking for atleast ½ hr"

There were some misconceptions that was encountered during the focus group conversations.

"Because I have sugar, they have told me not to lift heavy weight

"They have told me to avoid cold items and sweets so that I don't get wheeze"

"They told me to avoid brinjal and lemon rice"

2. <u>Trust in the health care team:</u>

Overall they overall had good opinion and trust in the treating team. Most wished to hear from the doctors that their disease is cured and that they could stop further medications. Even though for most of them, this is not feasible, their desire to live a life free of the disease and the amount of impact it had in their minds was clearly evident from these sessions.

"Doctors and the sisters they speak to me nicely and explain about all the medicines clearly. When I have doubt they explain"

"I expect them to tell me all my blood tests are normal. Doctors talk to us well and say we will become alright soon"

"Every time we come I expect doctors to say that Iam better and that they can try to stop my medications and observe"

"Every time I expect them to say some good solution for my wheezing.But they always advise me to continue my inhalers"

"I also expect them to tell me that my disease has become all right and that I should stop my inhalers"

"I expect them to tell me to stop all my injections one day soon. Since I have been coming for a long period, every time I wish doctors tell me to stop my medicine and tell me that my disease is cured. But I know I have to take these injections lifelong"

"I expect doctors to tell me that my sugars have become normalised and that I don't have to come any further for my medical check-ups and don't have to take any more injections"

"When we have problems, they admit us immediately and the care is given fast. That is a good thing about this hospital, even though we have to wait longer"

All the participants expressed the families' financial difficulties and wanted the treating physician to beconsiderate and give concession for treatment.

"My father is struggling to get money for my treatment. So I expect them to give some concession for my treatment"

"I don't have my father. My mother stitches clothes and with that income, she supports my studies and medical expenses. It is very difficult for her. So I expect some concession from the doctors"

3. <u>Clarification of doubts:</u>

Most of the participants shared that they were able to clarify their doubts with the doctors as well as with the support staff.

"There are no confusions with the instructions. In the pharmacy also they clearly write and tell us how and when to take the medicines"

"We always remember what the doctors tell me. More than me my parents are very aware of my medications"

"Every time we have doubts we clarify it in the pharmacy"

"Whatever problem we have we are able to tell to the doctors. They also ask every time whether we have any issues. the sisters and diet sisters also teach us about sugar and clarify whatever doubts we have."

"Whatever doubts we have, we are able to ask the doctors every time. They explain to me in detail all the foods that are to be avoided to keep sugar under control.

Medication related factors

1. **Forgetfulness:**

It was observed that forgetfulness is one major cause for noncompliance to the medication regimen. Most of the participants said they tend to forget to take their medicines when they are in a hurry to school/tuitions. It is parents who constantly remind them to take their medicines most of the times.

"When I have to get ready to school in a hurry, I forget my inhalers sometime"

"When we are in a hurry to go to school, even though we think we should take the puff, but I forget".

"Morning I go to tuition at 6.30 am and I am in a hurry to go to school. So I forget to take my puffs sometime"

"Many times I keep forgetting and have not taken the medicines. Because we get ready and run fast to school, I forget to take my inhalers in the morning. Even when we are going somewhere urgently I will forget to take the inhalers"

"I lose my inhalers somewhere. So I will miss few days' doses. While taking it to playground, I will misplace it somewhere"

"I never miss my medicines. Only if I take my medicines regularly can I live. So I will be scared and I will take my medicines. How much ever busy I am, I will always take my injections and only then I will do my other works"

2. **Difficult situations at home:**

Some of the participants expressed that when there are difficult situations at home eg. a death/fight, they forget to take their medicines.

"If there are some problem at home, I will miss my doses. If there was some death at home, I will miss my doses. But my mother will always tell me to forget the problems at home and take my medicines regularly"

"Even at my home when my grandfather died I did not tke my insulin. Immediately my sugars increased. My mother scolded me and asked me to take my insulin. After that I have never missed my insulin"

3. **Worry about side effects**:

They had worries regarding side effects of medicines. But they all remarked that despite the side effects they try to be compliant. And if they experienced side effects themselves, they might skip doses.

4. <u>Cumbersome treatment schedule</u>:

Some of the other difficulties they encounter with the medication are the confusions in understanding treatment regimens. They found treatment regimens cumbersome. They suffer emotional disturbances when disease keeps recurring. They are upset when the treatment regimen needed to berepeated or accelerated They feared social stigma and being discriminated against by the peer group if they are found taking medicines during school hours.

"*Many times I forget what the doctors have told me even before I reach home. I will say one dose and my mother will say another. Finally, I will take the dose as I like"*

"*Sometimes the insulin doses become confusing. Then we call the diabetic sister and get it clarified"*

"Sometimes when I feel why should I alone face these problems; I stop taking puffs for few times. During school days I take my inhalers regularly, but on holidays I delay taking inhalers and sometimes forget to take them".

"At afternoon in the schools, I will feel uncomfortable if my friends see me taking my injections. So sometimes I will not take my afternoon injections. In a month, I would not have taken my injection at least 5 times"

"Sometimes I will think that others will laugh at me, so I will not use inhalers in the school hours"

5. Resisting the normal temptations:

The participants explained that treatment instructions that restrain them from leading a normal life are often not followed. They also said that dietary restrictions that are implied as part of the treatment regimen are very difficult to follow.

"Taking inhalers regularly has become a big headache. I have to set aside time in the morning and night to take my inhalers. Not able to take the puffs regularly"

"*They have told me not to play; but I am not able to follow that instruction"*

"Because of sugar, they have told us to eat fruits and vegetables. But we will not have money for that. They have told us to exercise regularly,but I miss it frequently. I feel in those times as to why did I ever get this disease"

"They have told not to eat anything that is kept in the refrigerator. But because of desire I go ahead and eat it. Without my mother knowing, I will eat ice creams"

"I am not able to follow the instructions. My uncle will be coming from the village; He will be bringing some sweets. If we eat it will be good. My mother will give me one and hide the rest. My brother will eat. He will keep showing it to me and eat. When I see him I will be tempted. So I will also take one and eat it with me trying to control myself"

6. Fear of complications*:*

One factorthat was observed to contribute to compliance as shared by these adolescents was the fear of getting a complication related to the illness due to poor compliance. Such a possibility enabled them to strictly follow the treatment protocol.

"If I don't take my inhalers regularly, I will develop sore throat and chest discomfort immediately. Then I will take the blue colour(salbutamol) inhaler. Then I will become alright. So I try not to stop inhalers"

"If I don't take my insulin regularly, I will develop giddiness, abdominal pain. Immediately I will take 2 extra points of insulin. I miss my doses very rarely doctor"

"If I don't take my inhalers in the night, morning itself I will get wheezing. Then I will take an extra puff and then it will become alright. I miss my doses my infrequently. Because I develop wheezing immediately I will be scared to stop them. Even if it is in the night at 1 am, I will take my inhalers"

Socioeconomic factors:

Participants in all the 3 groups said that there were financial constraints in their families. They expressed the various difficulties their families faced while supporting their medical needs.

1. **<u>Financial debts in the family:</u>**

Most of the families seemed to have had debts because of the medical expenses.

"But when we buy medicines we will not have enough money. After taking a loan only we will purchase medicines. We take loan with a lot of interest every time to buy my medicines ".

"Doctors have told me to take diabetic diet. So lots of money is spent for that. If I ask fruits, my mother becomes upset and tells me that we don't have enough money and in anger tells me why I got the disease"

"My father and mother go for daily wage labour and they are managing my household expenses and my medical expenses. It is very difficult only and I feel very bad"

"Every time we come for check-up my mother borrows money from others and brings me."

"We usually borrow money from neighbours and come. Parents don't tell their difficulties in arranging money for my treatment. Sometimes because we don't have money, medicines might get little late"

"Somehow they will borrow money and get my medicines on time"

"Father is only finding difficulty to manage financially. We have only one cow and my mother is also going for daily wage work."

2. **Selling of property**:

A majority of the participants said that their families had sold their property little by little to meet monthly medical expenses and unexpected hospital admissions due to the complications. The participants were also aware of the specific details of the financial constraints the families dealt with. For example, they seemed to know that the family had to sell family heirlooms or property to spend for the treatment, that both parents had to work to make ends meet.

"After selling my mother's gold we buy my medicines. Even to buy my notes and books, we get money from someone else"

"My father has sold our house to manage my medical and our school needs. Even now when my father goes to take loan, people will ask us to first repay the initial amounts and then to take new debts".

"2 months back I was admitted in the hospital for 2 weeks. My mother sold her chain and with that money we managed the expenses"

"Once I had pain while passing urine. To meet all the expenses during that time, my mother had sold her gold ear ring and brought money for my medical expenses"

3. <u>Extended family support</u>:

Most of the participants spoke about financial support that the extended family gave. This is indicative of a close knit family system prevalent in the country and seems to work as a positive factor for an adolescent with chronic illness. As some of the participants said, the parents' employers too seem to help them in times of need.

"When we don't have money we will call our grandfather and he will help us"

"Other family members support us. Somehow they will borrow money and get my medicines on time. I never missed medicines because of lack of money"

"My grandfather had retired from the military. He was helping us. After his death there is no one to help us"

"In my house my grandfather and uncle will help us if we are not able to manage"

"Many of my relatives will help me. My grandfather, uncles and my father's employer will help us with my medical expenses".

"My mother is the only sister for my aunty and uncle. So they all take care of us very well. Every time I go to their house, they give me some money. Even if I refuse, they

give me. But sometimes when we find it difficult to manage for my treatment, my parents borrow money and I will feel very upset"

Financial constraints did not seem to affect adherence since most of the families met the medical needs immediately by borrowing money from others, rather than leave the adolescent alone without any medications.

4. <u>Poor scholastic performance:</u>

The adolescents also expressed their concern that they were forced to miss school days because of the outpatient appointments, admissions in the hospitals and the frequent follow up visits. They reported that studies were affected and scholastic performance markedly decreased. There were a few who said that they were able to fair well in examinations and that the presence of disease did not affect scholastic performance.

"School classes are missed. Headmaster sometimes gets irritated because of frequent absence"

"When I am sick I will not be able to concentrate. Otherwise studies are not affected. I am able to perform well in academics also"

"Because I keep coming to hospital, I have to take leave frequently and because of that my studies are getting affected."

"My outpatient visits are always on Mondays. So we come the previous day to give the blood investigation. My teachers will always ask and sometimes scold me saying why I take leave on Mondays"

"Many times my studies get affected. During quarterly exams I was admitted for 15 days. And when I ask leave on Mondays to come for the OPD, my teachers will scold

me saying why doI have to take leave on Mondays and why can't I go to hospital on Saturday and Sunday. Even for festivals I don't take leave. Only for my wheezing I take leave. But for that also my teachers scold me. But I'm able to get 90% in all my subjects"

"Even for me during my public exam I was admitted in RUHSA(a community based primary health care uni of the main hospital) hospital for high sugars for 5 days.So I was not able to write my exams well and I was able to get only 300 marks (60%). Because of the disease I was not able to study well. I was able to get only average marks. Because I am not getting good marks my father is scolding me"

"I will be continuously coughing and will feel like vomiting. So I will not be able to concentrate in the class. The interest in studies also is affected. Even at home because I get wheezing and fever frequently I will not be able to study well. I get around 80 – 85% "Betsy, I'll leave the spaces without correcting. Wherever the green underlining comes, can you please check it?)

"Because of my outpatient clinic visits, whatever classes I miss, I go back and learn from my teacher and friends. Whatever is incomplete I will finish it . I will get good marks and I am able to study well. In the last exams, I got 93% in maths, science and 80% in other subjects".

"I become sick very often, so my classes are affected. I have to keep coming to the hospital. I am able to get only average marks. In a year, at least 2 months I am not able to go to school. I am also not able to eat what other children eat normally"

"I study very well. I am interested in maths and English. They teach me well and I will concentrate well in the class. I get above 90% in all my subjects. I have never failed in

any of my examinations. Even though I am taking medicines, I am able to concentrate in my classes. Only on the outpatient clinic days I miss my classes and it becomes difficult to understand. I am not going for any tuitions. Because of my family difficulties, I am not able to afford for tuitions and special classes".

"I am not able to concentrate well in the class when I get cough and wheeze. Sometimes marks become low because of this"

"I am not able to concentrate well on my studies and classes. Many times I keep thinking about my disease"

"It will be nice if we have OPDs on Sundays so that our school timings and studies are not affected"

5. <u>Good parental involvement in the treatment care:</u>

Most of the participants shared that they have good support from their parents and other family members. They also shared that they feel upset when they see their parents go through so much difficulty for their sake.

"*They always support me. They bring me regularly for all my appointments. They never discourage me"*

"Because of my disease we are not going anywhere else. All my family members always support me. If I forget to take my inhalers, my father and mother will tell me how much they suffer and that I should take my inhalers regularly without problem. After that I also will take it regularly without missing doses"

"Even if I forget to take my medicines my father and mother will remind me.Even if I forget my mother will come to my school and give me the injections"

"My father and mother will always be with me whenever I get my wheezing. How much ever important work they have, they will not go for it, instead they will be with me".

"Even if I don't take proper care of myself, my mother takes care of me very well. She only brings me on time for the medical check-ups when sometimes I refuse to come"

"I don't have my father. So my mother does extra tailoring and with that income she helps me with my medications"

"when we come to the hospital, my mother keeps telling me that my disease will become alright, and not to worry. And whenever we go outside, they bring me home on time to take my injections"

"There are no difficulties at home. My siblings help me in remembering to take my insulin even if I had forgotten"

6. <u>Interference in activities of daily living:</u>

They also opined that the normal desires of an adolescent like participating in the school events and eating out with others. Eating something delicious with other are all been affected due to their disease state. One sentence about inability to run fast because of the symptom.

"When athletics happen in my school, all other will be able to run fast. But I get wheezing immediately. So I used to feel bad thinking why am I suffering from this disease"

"Initially they did not allow me to join the cricket team because I had wheezing, but once when had improved, they are now allowing me to participate in the school team"

"They go out for picnics and exhibition. But my mother will be scared to send me. So I will not go. Friends will ask me to come and they will say that they will pay for me. But still mother will not let me go".

"I am sometimes not allowed to eat what other children normally eat

"I will participate all school activities. Even if I hesitate, my friends will pull me in".

"When I go to school, the other children are eating everthing and it is very tempting. But I cannot eat those. So I feel upset. If I ask doctors, they say I should not eat these. But I always have the desire to eat"

7. <u>Support system in school:</u>

a) <u>Fear of discrimination:</u>

Some of participants expressed their fear of a social stigma that the presence of the disease will create among the peer group. As HCP we could facilitate using a social worker or other, to visit the school and educate the class and teachers about this particular teen's illness and see ways in which they can support them. One of the main concerns for schoolmates would be whether the illness is contagious. If their doubts are cleared, then the school can be a major support in improving compliance.

"Only my best friend knows. She will recommend to sir for my permission to go to hospital. Sometimes my teachers become upset because I am taking leave frequently on Mondays. I feel sometimes if other school mates also know about my disease, they might stop talking to me saying that they also will get the disease if they are my friends. So I have not told anyone else except my best friend"

"Sometimes I also feel that they all might think if they interact with me then they also will get the disease. Because of this thought, I have not told many people what problem I have. Even if others get something(some illness), they might put the blame on me. So I avoid telling everyone about my disease"

2. **Good peer support:**

There was a diametrically opposite view regarding social stigma among some of the participants. For some of them, even though they feared it, they did not experience any stigmatisation or discrimination in real life, and they reported to have had a good support system in the school.

"Only in the schools we feel happy. They(schoolmates) never tease us. They always say that things will become alright"

"Friends don't tease us. They always encourage me. Very rarely when they tease I will feel bad about it."

"They don't say anything. They support me always. They give me permission to take my insulin also."

"I am happy at school, because I can sit and chat with friends at school and forget about many things. But when I am at home, I think about so many things and Ifeel upset".

"None of my friends make fun of me. They are always very supportive"

"My friends never tease me. They are always happy and we all enjoy together. They always encourage by telling me that I will become alright and they come home and speak well with my mother also"

"My friends also are supportive. They always ask me if I had brought my inhaler and whether I'm taking it regularly"

"My tamil teacher in the school also has sugar problem. She has told me not to worry and to be happy. She told me it will become alright and that I should take my injections regularly. They told me not to worry thinking about the disease"

PSYCHOLOGICAL FACTORS

Upset with the presence of the disease:

Many of the participants shared that they were psychologically upset at some points in time due to presence of a chronic illness in their life. The stress associated with coping with a chronic illness was seen clearly during their discussions. They also seemed to worry about prognosis for the disease. They also reported that recurrence of symptoms disturbed them markedly.

Some of the participants with diabetes mellitus seemed to ask "why?" they alone had to develop this illness. This group of patients in particular have annual retreat with their families and the treating team in a location away from the hospital. It was disheartening that these adolescents had not yet come to accept their illness. It would probably be useful for the treating team to know about their wishful thinking. They could respond by having more meetings for just the adolescent patients to address this problem.

"Doctors have told that by 12 years, my wheezing will settle. With that hope we have been coming regularly till now. But since I have wheezing even now, my hope is lost"

"Many times I cry to myself. Sometimes I cry to my mother asking why I got this disease"

"Many times I cry at home. My mother consoles me saying I will become alright. Even in school I would cry. Teachers ask me not to worry and to take my injections regularly."

"Many times I think why should I alone get this disease, and I stop taking my inhalers for some time"

"They told me that the balloon test was normal. So I was happy for 2 months. But again I developed wheezing needing admission in the casualty for 15 days. So I am feeling upset"

"What my mother expects is that her son should become alright. They ask me to come in three months. But within 3 months I keep getting infection and swelling of my body. Doctors keep asking if I take my medicines regularly. My disease is not coming under control. Mother is getting very upset. Sometimes I feel why should I take medicines. Even at school, if I fight with my friends also I decide to stop taking medicines. At home when my mother scolds me also I stop taking medicines. If I fight with my mother in the mornings and I go to school without taking the medicines"

"When I come to hospital and see elderly people suffering from wheezing, I would to think whether my disease will really get cured. And then I feel depressed"

"Last time when I was admitted a 10 year old boy was also admitted with sugar. On seeing him I felt why dowe all get this disease. And I felt bad about it"

"Once when I was admitted a younger brother studying in 4^{th} (grade) was also admitted. He also had kidney problem. For one whole day he did not pass urine and

his body and face were swollen. On the other bed, there was another brother who also had sugar was admitted. He kept having breathing difficulty. On seeing all of them I felt why should god give us these diseases and I was feeling bad. Even at home when I am alone, I keep thinking as to why I am having this problem. If it had not come, I would think that my life would have been better".

"I was admitted for 3 days last year. I saw an elder brother("anna", respectful term to indicatean older boy, not necessarily the patient's brother) taking nebulisations. After seeing him I was upset thinking whether my disease will be really cured or not"

Psychological burden shared with others:

In the midst of all the psychological disturbances, they expressed that they shared their difficulties with parents and friends. Few said they do not share with parents, because they don't want to trouble their parents with extra burden.

"I always tell my teachers and friends. Parents get upset, so sometimes I don't tell them"

"I always share with my father and mother. Everytime I feel upset I cry to my mother. I tell my mother"

"I don't tell anyone"

"I don't tell anything to my parents. Friends ask why I am sitting upset. I don't tell them anything. Teachers tell me to take my medicines regularly and they say then I will become alright"

Fear of isolation:

The fear of being isolated seems to have been there always in their minds.

"When friends see me taking inhalers, I feel bad. But I have 2-3 friends who also have wheezing. So theytell me that my problem will get alright and cured"

"When friends see me with swelling of face and make fun of me, I used to really feel bad and think as to why I got the disease. They always ask me and make fun of me why my legs are swollen and my face big. I always complain to my teachers and they understand and support me"

Coping well:

Some of the participants said that they are not worried about the disease and that they have learnt to cope up with it.

"I never get upset for any of these things. I encourage myself saying if I take my medicines regularly I will become alright"

Wish list

When asked to give a wish list to God if He appeared in front of them, the list seemed to have similar responses – disease to be cured and parents should be happy.

"*I will ask him for my disease to be cured"*

"I will ask him that my problem should be solved and my parents be healthy"

"I will ask that my father and mother should be happy and that I should not have any disease. I want to become a doctor. My parents want me to help other poor patients like me"

"My parents should be happy and my health should me normal. I want to become an artist or a doctor. I want to find new medicines for bad diseases"

"For me my parents and my health are important"

"My health should become alright soon. Since my father is not there, I want my mother to live longer. I will ask that all these pollutions should not be there. I want to become a doctor and then a collector"

"My health should be alright and parents should live longer.' I am a doctor only',my mother has told me. My mother told me if I do good to others, only good things will happen to me."

"I will ask that no one should get this disease. My parents should be happy. And my disease should be cured"

DISCUSSION

7. DISCUSSION

Demographic profile

Adherence to treatment among adolescents with chronic illness is an area neither studied in our community nor in the rest of the country. This project was undertaken to fill this deficiency so that in future, management of the many adolescents who are under our care can be improved.

Overall of the 239 adolescents, 37 % of the participants were girls and 63 % boys. 11% of the participants were from consanguineous families. In the study population 60.5% of the adolescents had 1 sibling and 23 % had 2 siblings. In the study, 47 % of the children were in middle school (5^{th} to 8th grade) , 29 % were in high school(9^{th} and 10^{th} grade) and 1.7 % were not going to school which were mainly due to their illness.

Among all parents, 44%had graduated from high school, 5% were professionals and 13% were not literate.The majority of the parents (52%) were skilled / semi-skilled or unskilled workers, 12.6% were semi-professional or professional, and 4.6% were unemployed.

Association between gender and socio economic status and adherence.:

58 % among boys were adherent and 67 % among girls. Both boys and girls were equal in their adherence. Among those in low SES, 59% were adherent ; in the middle SES 61% were adherent and in the high SES group 89%. There was no statistically

significant association seen between gender and adherence ; socio economic status and adherence in the study population.

Overall level of adherence to medication:

Using MMASit was revealed that of the 239 adolescents who participated in study,32 % had good adherence; 29 % had medium and 39 % had poor adherence. WHO estimates that, only 40- 50% of adolescents receiving medication for chronic illness are adherent(16). Bender et al(18) reported that 50% to 60% of adolescents were taking prescribed doses of inhaled medications.Murphy et al (19) noted that out of 161 adolescents with HIV only 50% reported adherence to the entire regimen. In this study, 60% adherence overall is more than the current evidence.

Disease wise rate of adherence

The most common chronic illnesses among our study population, were nephrotic syndrome(24.6%), asthma (23.8%) and diabetes mellitus (10.87%). Good adherence was observed among adolescents with nephrotic syndrome (43%)an diabetes mellitus (57%),whereas poor adherence was seen with asthma(61%).

The group wise association between various factors influencing adherence and the level of adherence was analysed using Chi square and p-values.

MEDICATION RELATED FACTORS

1. Difficulty in taking medicines

Of all the participants, 71% seldom had difficulties in taking medicines and following doctors orders. Of those, 69% had good adherence. Of those who said that they usually had difficulty taking medicines, only 42% had good adherence. When these 2 groups were analysed, p value was <0.05, indicating theat there was a statistically significant association between good adherence and no difficulty in taking medicines.

2. Need for using reminders:

71% of patients who seldom needed reminders for medication, had good adherence by MMAS scale. 54% of those who usually needed reminders had good adherence. A p value of 0.007, indicates a good associationbetween good adherence and not needing reminders. Becker et al(55) reported that use of reminders significantly improved adherence.

3. Missing pills:

66.5% of those who seldom missed their medicines had good adherencewhereas

12.5% of those who usually missed their medicines had good adherence,

A significant statistical association (p 0.0001) was observed between good adherence and not missing pill counts.

4. Understanding complications:

Among those who seldom understood the complications of non adherence to treatment, 54% had good adherence,and amongst those who usually understood the complications of non adherence to treatment, 65% had good adherence.

No statistically significant association (p 0.0993) was observed between good adherence and knowledge about complications. A study conducted by Bender et al among adolescent asthma patients (mean age of 10 years)using inhaled beta agonists and corticosteroids showed a significant noncompliance associated with lesser knowledge about complications of the disease (47).

3. Worry about side effects:

Among those who seldom worried about side effects of medications , 58% had good adherence and of those who usually worry about side effects, 77% had good adherence. AStatistically significant association (p 0.039) was observed between worrying about side effects and good adherence. This is in contrast to what is seen in other studies where worrying about side effects usually caused low adherence. In a study done by Cromer et all (42a) on Psychosocial determinants of compliance in adolescents with iron deficiency found that worrying about the side effects is an important factor for skipping medicines and thereby leading to poor adherence. In a study by .Lanskey S, et al(22) also showed a significant association between good compliance and not worrying about the side effects.

4. Complexity of the medication :

Among those who did not feel that their medication was complex,65% had good adherence and among those who usually felt that their medication was complex , 49%

had good adherence. There was no statistically significant association between good adherence and complexity of the medication regimen. Nevis TE et al in his study on non-compliance and its management in teenagers (42) reported that a complex dosing schedule and recommendations is associated with poor adherence. Blackwell B. et al(22b) also noted similar findings.

Health care related factors:

1. Trust in the treating physician and the team

In our study,99.5 % of the adolescents said they trusted their physician, but only 62% of them had good adherence. Hence there was no statistical difference (p 0.389) observed between adherence and trust in the physician.Shope J. in his study had noted that the trust and friendly rapport between the adolescent and the physician results in a better adherence. (41d) Becker MH, et al also observed that the trust the adolescent have on the physician and the attitude and interest from the HCP with regard to patient's well being seems to improve compliance(55)

2. Encouragement by health care team:

In our study we noticed that 99.5% of the participants reported that they were encouraged by the treating team every time they come for OPD follow ups. But only61% of them had good adherence which was not statistically significant(p 0.82). This finding is different from what other researchers have reported. Astudy by Andrea

et al (158) and Rosenberg CH (54) showed significant associationwith good adherence and the constant encouragement by the treating team. A similar association was noted by Dr. Rose as published in his work(24). The diametrically opposite finding in our study could be explained by financial constraints many of our patients have.

3. Knowledge about disease:

In our study, 94% of the adolescents reported that they were able to understand the information that is provided to them by the physician during their medical visits. But only 60% of them had good adherence. Hence there no statistically significant association (p 0.7874) seen with the understanding of the disease and the adherence. .Whereas in a study by Fielding Duff , compliance with treatment protocols was significantly shown to be associated with good understanding of the disease (41) . In another study by Tebbi et al regarding Compliance in adolescent cancer patients, significant association was observed between understanding of the disease and good adherence (41b). In another study of adolescents with cancer, compliers and noncompliers differed significantly in how better they comprehended the instructions that were given to them.(41c). Bender et al(47)on study with adolescents with asthma also showed a significant association.

4. Clarifying with the Health Care Physician :

Regarding clarifying doubts 88 % said they usually clarified their doubts with the physicians but they had a good adherence of 61% compared to 60% in those who seldom clarified their doubts. Hence there was no statistically significant association (p 0.9656) obtained between good adherence and clarying of doubts with the health care team.

Socio economic related factors

1. Managing the medical expenses :

Of all the participants, 86% had reported that they are able to manage their medical expences. But only 54% of them had good adherence whereas 61% of those who usually have financial difficulties had good adherence. This did not show any statistically significant association (p 0.1842) between good adherence and financial ability to support the treatment. Study by Windebank KP et al in adolescents with cancer found association between financial constraint and poor adherence(151)

2. Attending regular activities:

94% of participants reported that they are able to attend to their daily activity and they had 60% good adherence . Only 6% reported that they have inability to attend to their daily activities and they had 66% good adherence. Hence there was no significant association between good compliance and ability to perform regular activities. Where as there are various studies (151, 152, 153, 154) that show that poor compliance markedly affects the day to day activity. This difference in our study was probably because, daily activity for an average teenager in India is school and family related and less of outside of home, social activities.

3. Parental involvement:

Amongst the participants , 87% of them had good parental support. But only 53% of them had good adherence. There was no significant statistical association(0.834) observed between good adherence and parental support. There are numerous studies (42a , 43,44,45) that has found a significant association between parental support and

adherence. There are several factors that could be attributed to this absence of association between parental support and adherence in our population. Such as even though there is parental moral support, superstitious beliefs systems regarding illness and financial constarints may negatively affect adherence.

Psychological factors:

1. Feeling sad and adherence

Of all the participants, 80 % of them had reported that they had felt emotionally upset with the presence of the disease at some point. Of those who seldom felt sad about their disease ,70% had good adherence and of those who usually felt sad about their disease , 59 % had good adherence.There was no statistical significance (p 0.1380) noted between poor adherence and psychological disturbance. Studies done in adolescents with diabetes mellitus have shown that the poor glycaemic control(155) and a low turnover to follow up visits have an associated psychological factor(156). In another study (157) also poor adherence to treatment was seen associated with the psychological and behavioral problems they experience to the disease.

2. Sharing of difficulties

In our study, over all 60% had self reported that they usually share their difficulties with family and friends but only 58% of them had good adherence.Whereas among those who seldom shared their difficulties , 66% had good adherence. There was no statistical significant association (p = 0.29) observed between good adherence and sharing of difficulties with family and peer support group. Study done by Graetz et al(

35) in adolesscents with cystic fibrosis showed significant association between good adherence and sharing of diffulties.

CONCLUSION

8. **CONCLUSION**

1. We found that good adherence was observed in 32.2%, 28.8% had medium adherence and 38.9% had poor adherence using MMAS score.

2. There was significant association observed between good adherence and never missing to take pills, knowledge about the disease and complications. However in our study we did not find any significant association between adherence and financial status, emotional disturbance.

3. From the Qualitative analysis, the factors that were observed to be influencing adherence in our study population were forgetfulness, fear of being stigmatised, significant financial constraint, worry about side effects.

4. It was also observed that most of the adolescents in our setting had good parental involvement in the ongoing medical care of the child.

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9. BIBLIOGRAPHY

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APPENDIX

10.1 Patient Information Form

Introduction

I am Dr. A. Betsy Sherba ,working as a PG registrar in the Department of Child health doing a thesis on assessing the adherence to medication to chronic illness in adolescents attending the speciality OPDs of the Department of Child health, Christian Medical College, Vellore from November 2015- June 2016. I kindly request you to participate in the study.

Purpose

Not taking complete treatment is a major problem in adolescents(10-19 yrs age) with chronic diseases. My study is to see how many follow the entire treatment, so that the result will help in promoting some interventions that improve treatment adherence and better health and life style in adolescents.

Voluntary Participation

Your decision to participate in this study is entirely voluntary. It is your choice whether to participate or not. If you choose not to consent, all the services you receive at this clinic will continue and nothing will change. You may also choose to change your mind later and stop participating, even if you agreed earlier, and the services you receive at the clinic will continue.

Procedures and Protocol

You will be given a questionnaire which you can fill it up by responding the yes/No type and the multiple choice questions. This is just a one time contact questionnaire.

Then you might be further invited to participate in Focus group discussions along with adolescents who have similar health issues as you do.

Side Effects and risks :

Since this is only a self reporting questionnaire to assess the adherence , there are no side effects/risks involved.

Confidentiality

The information that we collect from this research project will be kept confidential. Information about you will be collected from the research will be put away and no-one but the researchers will be able to see it. Any information about you will have a number on it instead of your name.

Right to Refuse or Withdraw

You do not have to agree to taking part in this research if you do not wish to do so and refusing to participate will not affect your treatment at this Centre in any way. You will still have all the benefits that you would otherwise have at this Centre. You may stop from participating in the research at any time that you wish without you losing any of your rights as a patient here.

Who to Contact : If you have any questions you may ask them now or later, even after the study has started. If you wish to ask questions later, you may contact any of the following: Betsy Sherba , PG registrar, Department of Child health , o416 2283348

10.2 Informed Conset

Certificate of Consent

1. I have been invited to participate in research of "To assess the rate of adherence to medication in adolescents with chronic illness attending the Specialty OPDs of the Department of Child Health, Christian Medical College, Vellore from November 2015 to October 2016 and to explore factors influencing adherence to treatment by means of qualitative study using focus group discussions".I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I consent voluntarily to participate as a participant in this study.

Print Name of Participant

Print Name of Parent or Guardian_____

Signature of Participant _____

Date _____

Day/month/year

I have witnessed the accurate reading of the consent form to the participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness_____ AND Thumb print of participant

Signature of witness _____

Date _____

Day/month/year

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant. I confirm that they were given an opportunity to ask questions about the study, and all the questions asked by them have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the consent

A. Betsy Sherba_____

Signature of Researcher /person taking the consent

A. Betsy Sherba_____

Date _____

10.3 Informed Assent

Certificate of Assent

I have been invited to participate in research of "To assess the rate of adherence to medication in adolescents with chronic illness**".** I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I agree to take part in the research.

Name of child

Signature of child:

Date:_____

If illiterate:

I have witnessed the accurate reading of the assent form to the child, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely**.**

Name of witness (not a parent) AND Thumb print of participant

Signature of witness :

Date :

Day/month/year

Statement by the researcher taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the child understands the purpose of the study.

I confirm that the child was given an opportunity to ask questions about the study, and all the questions asked by him/her have been answered to the best of my ability.

Name of Researcher : A. Betsy Sherba

Signature of Researcher

Date :

Day/month/year

10.4 Study Proforma

Adherence to treatment among adolescents with chronic illness

Proforma

Hospital number : Serial number : Date :

Demographic data

Name : Date of birth:

Sex : Residence (distance from health care facility) :

Accompanied by : No of member's in the family :

Education : Family SES :

Parent/guardian's work: Education:

Monthly income:

Diagnosis :

Date of diagnosis :

Hospital admissions in the past :

Monthly expenditure for drugs :

Last Medication visit :

Frequency of hospital visits in last 6 months:

MORISKY MEDICATION ADHERENCE QUESTIONNAIRE(MMAS-8)

Question	Patient Answer (Yes/No)	Score Y=0; N=1
1. Do you sometimes forget to take your medicine?		
2. People sometimes miss taking their medicines for reasons other than forgetting. Thinking over the past 2 weeks, were there any days when you did not take your medicine?		
3. Have you ever cut back or stopped taking your medicine without telling your doctor because you felt worse when you took it?		
4. When you travel or leave home, do you sometimes forget to bring along your medicine?		
5. When you feel like your symptoms are under control, do you sometimes stop taking your medicine?		
6. Taking medicine every day is a real inconvenience for some people. Do you ever feel hassled about sticking to your treatment plan?		
7. Did you take all your medicines yesterday? Y – 1 ; N - 0		
8. How often do you have difficulty remembering to take all your medicine? A. Never/rarely B. Once in a while		A = 1; B-E = 0

C. Sometimes D. Usually E. All the time		

Total score

FACTORS INFLUENCING ADHERENCE, QUESTIONNAIRRE

Health care service related

1. Do you trust your doctor? Never, Seldom, Usually, Frequently, Almost, Always
2. Do you trust the health care team? Never, Seldom, Usually, Frequently, Almost, Always
3. Do you feel encouraged and motivated by the health care team in your visits? Never, Seldom, Usually, Frequently, Almost, Always
4. Do you understand the information concerning your disease and treatment provided to you? Never, Seldom, Usually, Frequently, Almost, Always
5. Do you clarify your doubts about your treatment? Never, Seldom, Usually, Frequently, Almost, Always

Treatment related

1. Do you have any difficulties taking the pills? Never, Seldom, Usually, Frequently, Almost, Always
2. Do you use reminders to take your medications at correct times? Never, Seldom, Usually, Frequently, Almost, Always
3. Number of drugs that you are taking : 1, 2, 3, >/4
4. How often do you miss your medicines? Never, Seldom, Usually, Frequently, Almost, Always

5. Is an increased number of medicines is hindering your medication adherence? Yes / No
6. Do you understand the complications of not adhering to the treatment regimen? Never, Seldom, Usually, Frequently, Almost, Always
7. Are you worried about the side effects? Never, Seldom, Usually, Frequently, Almost, Always
8. Do you feel the medication regimen is complex to be understood and followed? Never, Seldom, Usually, Frequently, Almost, Always
9. Have you ever felt that medication is not effective : Never, Seldom, Usually, Frequently, Almost, Always
10. Have you adopted alternative medicine for treatment of your condition? Yes / No

Socio economic related:

1. Do you feel you get your family support in your treatment ? Never, Seldom, Usually, Frequently, Almost, Always
2. In your family, does anyone help you to remember to take the medicine? Never, Seldom, Usually, Frequently, Almost, Always
3. Are you able to manage the financial needs for the treatment every month? Never, Seldom, Usually, Frequently, Almost, Always
4. Are you able to attend to your regular activities? Never, Seldom, Usually, Frequently, Almost, Always

5. Is access to health care by means of distance and travela difficulty for you? Never, Seldom, Usually, Frequently, Almost, Always
6. Are you able to attend to your regular clinics without missing an appointment? Never, Seldom, Usually, Frequently, Almost, Always

Pshycological

1. How often have you felt sad about the disease? Never, Seldom, Usually, Frequently, Almost, Always
2. Does your emotional status affect you while adhering to your treatment? Never, Seldom, Usually, Frequently, Almost, Always
3. How frequently do you share your difficulties with medication with family/friends/health care professionals? Never, Seldom, Usually, Frequently, Almost, Always

10.5 Trigger Questions for the FGD

Focus Group themes Consolidated

A. Health service related factors

1. What are all the informations given to you and what do you know about your disease?
2. What are your expectations during every medical visit from the treating team?
3. Are you allowed to ask doubts and if so how are your queries answered?
4. How far are you able to follow the instructions given to you?

B. Medication related factors

1. What are the difficulties in taking your medicines?
2. Are you worried about the side effects? And how far does it affect your adherence?
3. When all do you forget to take your medicines?
4. Have you had confusions regarding the medication regimen?If so how are they sorted out?
5. Do you understand the complications that can happen if you don't take your medicines?

C. Socioeconomic factors

1. How does your parents manage the finances needed for your treatment?

2. How much impact has the disease have on your daily living – your work at home , school and time with friends?

D. Psychological factors

1. What kind of support system you experience at home and at school to share your difficulties?
2. How has the disease affected you psychologically?
3. Tell us your wish list if God appears before you now.